REPORT ON PROCEEDINGS BEFORE

PORTFOLIO COMMITTEE NO. 2 - HEALTH

HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

CORRECTED

Virtual hearing via videoconference on Tuesday 5 October 2021

The Committee met at 10:30.

PRESENT

The Hon. Greg Donnelly (Chair)

Ms Cate Faehrmann
The Hon. Wes Fang
The Hon. Emma Hurst (Deputy Chair)
The Hon. Walt Secord

The CHAIR: Good morning and welcome to the tenth hearing of the Portfolio Committee No. 2 - Health inquiry into health outcomes and access to health and hospital services in rural, regional and remote New South Wales. The inquiry is examining health outcomes, access to services, patient experience, planning and capital expenditure in rural, regional and remote New South Wales. Before I commence I would like to acknowledge the Gadigal people, who are the traditional custodians of the land on which this Parliament sits. I also pay respects to Elders past, present and emerging of the Eora nation and extend that respect to other Aboriginals who may be viewing the broadcast over the course of the day. We welcome you.

Today's hearing is being conducted virtually. This enables the work of the Committee to continue during the COVID-19 pandemic without compromising the health and safety of members, witnesses and staff. As we break new ground with the technology, I ask for everyone's patience through any technical difficulties we may encounter over the course of today. If participants for some reason lose their internet connection and are disconnected from the virtual hearing, may I ask them to rejoin the hearing by using the same link as provided to you by the Committee secretariat.

Today we will be hearing from a number of stakeholders including peak cancer organisations, the New South Wales Medical Staff Executive Council and research organisations. I thank everyone for making the time to give evidence to our public hearing today. Before we commence I would like to make some brief comments about the procedures for today's hearing. While parliamentary privilege applies to witnesses giving evidence today, it does not apply to what witnesses say outside of their evidence at the virtual hearing. I therefore urge witnesses to be careful about comments you may make to the media or others after you have completed your evidence today before the inquiry. Committee hearings are not intended to provide a forum for people to make adverse reflections about others under the protection of parliamentary privilege. In that regard it is important that witnesses focus on the issues raised by the inquiry's terms of reference and avoid naming individuals unnecessarily.

All witnesses have a right to procedural fairness according to the procedural fairness resolution adopted by the Legislative Council in 2018. There may be some questions that a witness could only answer if they had more time or with certain documents to hand. Accordingly, witnesses will be advised that they can take a question on notice and provide an answer within 21 days. Today's proceedings are being streamed live and a transcript will be placed on the Committee's website once it becomes available.

Finally, I have a few notes on virtual hearing etiquette to minimise disruptions and assist our Hansard reporters. Can I ask Committee members to clearly identify who questions are directed to and could I ask everyone to please state their name when they begin speaking. Could everyone please mute their microphones when they are not speaking. Please remember to turn your microphones back on when you are getting ready to speak. If you start speaking whilst muted, please start your question or answer again so it can be recorded in the transcript. Members and witnesses should avoid speaking over each other so everyone can be heard clearly. Finally, also to assist Hansard, may I remind members and witnesses to speak directly into the microphone and avoid making comments when your head is turned away.

EMMA PHILLIPS, Executive Director, Can Assist, sworn and examined

MAJELLA GALLAGHER, Relationship Manager, Can Assist, sworn and examined

JEFF MITCHELL, Chief Executive Officer, Cancer Council NSW, sworn and examined

ANNIE MILLER, Director, Cancer Information and Support Services, Cancer Council NSW, affirmed and examined

The CHAIR: Thank you to everyone who is joining us on the internet today. We will now proceed with our first set of witnesses for the public hearing this morning. Thank you to the four of you, who I know are very busy with your respective responsibilities with your organisations. We appreciate you carving out some time and making yourselves available today for our public hearing. Before we commence can I just note and thank, first of all, Can Assist with respect to the submissions that have been received. We received what is the first submission that came in, which is submission No. 34 to the inquiry, and then we subsequently received a submission from you, Ms Gallagher, as the Relationship Manager, and that stands as submission No. 710. So Can Assist have effectively two submissions before us, and we thank you very much for those. They can be taken as read by the Committee.

If we move then to Cancer Council NSW, thank you very much for being available today. I just note for the record the receipt and the processing of your submission. It stands as submission No. 173 to the inquiry and, as with Can Assist's, it has been processed and uploaded onto the webpage for the inquiry and stands as evidence to the inquiry. What I will do before we move to questioning is ask both organisations to make an opening statement. I am not quite sure who will make it. With respect to Can Assist, noting that they have got two separate submissions, I will invite both participants to say a few words. But in both cases, for each organisation, if we can keep the opening statements to a few minutes that will maximise the opportunity for the Committee members to proceed with their questions. Are people happy with that format? Wonderful. We will commence with Can Assist. Ms Phillips, may I invite you to make an opening statement?

Ms PHILLIPS: On behalf of Can Assist and our 3,000 statewide volunteers, I thank the Committee for the opportunity to provide our perspective. Our submission focuses on three key areas of concern. Firstly, Isolated Patients Travel and Accommodation Assistance Scheme [IPTAAS]. A highly visible and widely accessible travel and accommodation scheme must be the centrepiece of any vision for better health outcomes for rural, regional and remote Australians. However, our anecdotal and quantitative intelligence, as reported in the tabled IPTAAS document, overwhelmingly tells us that most patients are unaware of the scheme and almost all patients find the forms too complex to navigate. For those that do persevere, rebates are inadequate. Travel and not-for-profit accommodation rebates have been static since 2015. Accommodation facilities like ours in Wagga Wagga offer a key gateway into the regional health system and for the most part have carried an ever-increasing expense base. This is not sustainable.

Can Assist and the Regional Accommodation Providers Group recently met with Stephanie Williams and three of her colleagues from NSW Health. Our IPTAAS concerns and remedies were heard, though there is little that can be done without additional budget. Of further concern is that despite Minister Hazzard's declaration as per *Hansard* on 11 February 2021 that he was "happy to instruct Health to look at the issues", they have received no such instruction. Secondly, radiotherapy access and viability. Recipients of ours, Danielle and Tony, made 132 trips over 2½ years, travelling around 24,000 kilometres, seeking treatment for their seven-year-old daughter Halley and 74 per cent of this travel related to radiotherapy treatment. Whilst the treatment itself is often as short as 15 minutes, the frequency, length of treatment and its delivery as an outpatient makes it uniquely expensive for those that do not live close to these services. The indirect impacts are financially devastating. In Halley's case, her mum stopped full-time work, her dad dropped back to two days a week and Halley's grandmother left her part-time job.

The Federal Government has promised $35 million to help build an additional seven radiotherapy sites throughout country New South Wales. For these services to be viable at no out-of-pocket cost for local residents, the New South Wales State Government must be prepared to either operate them themselves or be willing to provide a reasonable co-payment to private operators. The State Government makes these co-payments in metropolitan areas and this approach is routinely practised in other States across Australia. As far as we know, NSW Health has refused all partnership proposals. Four of the seven grants remain unawarded. Why leave Federal grant money on the table and deny equitable access to treatment?

Finally, staffing issues: under-resourced and undervalued. GPs are where it all begins, yet our communities wait too long, some up to four weeks, to access what is often a junior GP. In Halley's town the long-term doctors had closed their books. Medical clinics with less experienced staff were her only alternative. Kudos to her mum, who trusted her gut and persisted when three separate doctors over three separate appointments told her not to worry and sent her home. Halley was later diagnosed with brain cancer. Specialists are even scarcer. Social workers offer a vital service. Their case loads are exploding and they are stretched across the spectrum of care. Sadly, many of their contracts are only one year, despite years of experience and commitment. Many of our volunteers have inappropriately become quasi social workers, filling these gaps. Thank you.

The CHAIR: Thank you very much for that very detailed and clear opening statement. Thank you, Ms Phillips. Ms Gallagher, would you like to make an opening statement?

Ms GALLAGHER: Chair, we wrote that speech with a view to both of our submissions.

The CHAIR: No, that is fine.

Ms GALLAGHER: I will not add anything, only just to check that you actually received the additional document around the presentation that we gave to NSW Health? So you should have the two submissions and there was also a pdf document that you hopefully received as well that you did not mention.

The CHAIR: Yes, thank you very much. I can confirm that has been received.

Ms GALLAGHER: Excellent.

The CHAIR: Thank you very much. That augments very nicely the material we have already and no doubt the evidence we will hear from both of you this morning, so thank you, Ms Gallagher. I now move to the Cancer Council. Mr Mitchell, as the CEO, will you be giving the opening statement?

Mr MITCHELL: Yes, I will. Thanks, Chair. Firstly, I would like to acknowledge the traditional custodians of the land on which we meet. For me, that is the Wodi Wodi people of the Dharawal nation, down here in beautiful Kangaroo Valley. I would also like to thank the Committee for the opportunity to give evidence at the inquiry. Cancer contributes the largest burden of disease in Australia. In New South Wales, over 51,000 people are expected to be diagnosed with cancer and over 16,000 will die of cancer in 2022—more than stroke and heart disease combined.

Cancer outcomes in New South Wales are among the best in the world, yet for people living in rural and remote New South Wales outcomes remain poor compared to people living in metropolitan areas. There has been little progress in narrowing this gap in the past 20 years. Everyone with cancer deserves the best chance of living well and yet evidence clearly demonstrates that the chance of being diagnosed with cancer and dying from cancer increases with distance from major centres. Unfortunately, the reality is that a person's experience of cancer is a postcode lottery.

For people with cancer in regional New South Wales, a host of issues affect whether they can access the best possible cancer treatment and care when they need it. One of the clearest things that we hear from people we assist is that they did not expect a cancer diagnosis to be so expensive. The out-of-pocket costs faced by people with cancer are higher for people outside of metropolitan areas, so much so that one in five people with cancer in regional New South Wales report that they skip health appointments because of the cost. People in regional New South Wales are less likely to have access to a nearby public hospital and, for those that cannot be treated locally, travelling to and from treatment and staying away from home comes at an enormous physical, emotional and financial toll. Access to supportive care services can be limited in regional New South Wales and people with cancer can struggle to navigate the system, which is fragmented across different providers and locations.

Cancer Council NSW works closely with people affected by cancer in regional New South Wales, providing essential services such as transport, emergency financial support, accommodation, information and supportive care. Our recommendations are based on evidence, from what we hear day to day—day in, day out—and from people affected by cancer. For this inquiry we also heard from more than 300 people who responded to our cancer in the regions survey. Cancer Council NSW believes there are things that can be done by the New South Wales Government quickly that will significantly improve the quality of life for people with cancer.

People should not be forced to choose between getting cancer care or paying their bills. Lifting reimbursement rates for the Isolated Patient Travel Accommodation and Assistance Scheme and broadening its eligibility will go a long way to relieving this financial and emotional toll. Investing in care coordination will help prevent people from getting lost in the system, by linking them to the treatment options and the services that are available to support them. And, importantly, we believe addressing out-of-pocket costs for cancer treatment will reduce inequality, because your postcode should not determine whether you can afford treatment or not. These inequalities do not just exist across the country and city divide; out-of-pocket cost inequalities also exist between different regional communities.

Finally, I think it is important to sound a warning about what lies ahead as we recover from what has been one of the greatest public health challenges in a century. COVID-19 has stopped many things, but it did not stop cancer. The delays in screening, diagnosis and interruptions to cancer care will see cases rise, we believe quite sharply and for an extended period, in the near future and the nature of the cancers diagnosed are very likely to be more advanced. The other lesson from COVID-19 is that we need to urgently address the inequalities in our health system—inequalities that existed before the pandemic. If we do not have a plan to address the ongoing impact on access to cancer care and services, COVID-19 will only amplify those inequalities. Thank you, Chair.

The CHAIR: Thank you, Mr Mitchell. That was a very clear and helpful opening statement, which I am sure will facilitate a number of questions. We will proceed now to questions from Committee members. We have, effectively, about 10 minutes for each group around the table, to take us through to around quarter past 11 or thereabouts. We will start with the Opposition. The Hon. Walt Secord?

The Hon. WALT SECORD: Thank you, Mr Chair, and thank you for your opening statements. Evidence that the Committee has heard over the last few months has been absolutely damning involving rural and regional areas. Mr Mitchell, in your opening statement, to paraphrase, you said that cancer treatment in the city is probably the best in the world. How would you describe access to cancer treatment in rural and regional centres in New South Wales?

Mr MITCHELL: It is very dependent on what is available nearby. As we mentioned, quite often, I am sure you would understand, people are often required to travel distances and to stay away from their home. That affects all parts of the cancer journey, so starting with access to screening, access to diagnosis in a timely manner and then of course, importantly, access to treatment and care. The availability of public facilities—you know, one of the case studies we have looked at is that if you have breast cancer and you are based in Wagga, for example, you would need to access the Riverina Cancer Care Centre [RCCC] there, which is a privately owned facility. Your out-of-pocket costs for that treatment would be just short of $3,000 for what would be considered a normal course of treatment. Whereas if you were living in the lower North Shore you would access Royal North Shore and there would be zero out-of-pocket costs. I just do not think any of us should be comfortable that that situation is allowed to continue.

The Hon. WALT SECORD: Are there significant variations even within the country? Because I understand in your submission, on page 7, you talk about the following:

> From Bathurst to Burke, Narooma to Narrabri, there is clear evidence of higher cancer incidence, poorer survival and unwarranted variations in clinical care for people with cancer …

Do you find that even within rural and regional areas there are huge discrepancies in access to treatment, to cost and to—I am sorry to say—the survival rates?

Mr MITCHELL: Look, that is true and there is a wealth of information that would support that hypothesis. Even if you look at the Cancer Institute NSW outcomes that they track, you can see that cancer care treatment outcomes and indeed ultimate health outcomes for patients across regional areas can vary quite widely.

The Hon. WALT SECORD: Ms Phillips, would you say that evidence or information to your organisation is that—would you say that rural and regional people, I do not know how to phrase this, are dying unnecessarily or prematurely due to lack of access to cancer treatment in rural and regional areas?

Ms PHILLIPS: Whilst I do not have the evidence in front of me to give you the stats, I would say that the disparity in access the further that you move away from a metro would indicate that that would be the case. Because we see people that come forward and ask for help, and it takes a lot for people to come forward to ask for help. We hear stories about the access just to get to a GP, like I tabled. So how many people are not coming forward to a GP? I cannot tell you, because they do not come to us. But I do see the issues with people just coming forward to us and the feedback from the grassroots on the ground about how hard it is to get in to a doctor. I can only surmise that then echoes through to the entire spectrum of care that we see and so people do not get the same opportunities as I do in the city with a bevy of choices around me.

The Hon. WALT SECORD: Mr Mitchell, you talked about people skipping appointments. What do people say or tell you—what does skipping a cancer treatment appointment involve, emotionally, physically? How does it impact on the patients?

Mr MITCHELL: If I may, I would ask my colleague Annie Miller perhaps to address that. I think she has got a clearer [disorder].

The CHAIR: Thank you, Ms Miller, that would be great.

The Hon. WALT SECORD: Yes, thank you, Ms Miller.

Ms MILLER: We hear everything from the very initial diagnosis on our information and support line. Someone in the rural areas may say to us, "I think I have just been diagnosed with cancer but, to be honest, I honestly can't afford to leave my property. I have a family to support, and they want me to go to the city, and I just can't afford it, so I've actually decided that I'm not going to go through with this but I'd like to know my options. There is no one here locally that can help me. We can't afford to travel to the city and stay in accommodation," and they choose not to follow through with treatment. They are examples, but also going through—

The Hon. WALT SECORD: [Disorder].

Ms MILLER: Sorry.

The Hon. WALT SECORD: Sorry, could we continue? So you have examples of people who have cancer diagnosis—

Ms MILLER: Yes.

The Hon. WALT SECORD: —and because of distance and cost, and lack of rebates or insufficient rebates, they decide not to seek treatment?

Ms MILLER: That is right.

Ms GALLAGHER: Sorry, could I just interrupt there? Sorry, Annie. From a Can Assist perspective, we frequently had social workers and allied health workers tell us that if it wasn't for us people would not continue their treatment. We have also had recipients who tell us directly that they would have had to have sold their houses had it not been for us, and they would not have been able to afford it. It is all about cost, and the further you are from the treatment facility, the more it costs. It is not just the travel and accommodation. Travel and accommodation is key, and if IPTAAS was delivered better, more people would know about it. When they are actually deciding whether or not to have treatment right back in the early stages, if people were more aware of the availability of IPTAAS and what it could do for them, we do think that would help.

But even notwithstanding IPTAAS, the further away you are—you've got the travel and accommodation, which is obvious, but also because you are travelling outside of your family community, you are almost invariably having to take a carer with you, so that means you've got loss of two incomes. When there are children involved, it often means, as in our opening speech, you have extended family that also lose income. So there are indirect costs there that have to be considered; the actual travel and accommodation costs; and, as Mr Mitchell pointed out, if you are unfortunate enough to be in the Murrumbidgee, you are exposed to the RCCC, which is the only private hospital, major regional hospital centre, in rural-regional New South Wales. There is a private-public partnership there, but it is not complete, so there are still be out-of-pockets. Whilst we have private-public partnerships in metropolitan areas and routinely across the country where out-of-pockets are zero, we do not have that in Wagga, so there is that additional medical issue as well.

The Hon. WALT SECORD: Ms Miller, would you have many examples or cases of people deciding not to pursue treatment in rural and regional areas because of distance but also because of costs and lack of access to public facilities?

Ms MILLER: Yes, we do. I do not have the exact numbers, but we do. It is a theme that comes up regularly. May I also say that we also speak with people who are going through treatment, and that might be an extended treatment. They may get to the stage where they are "starting to juggle what my bills are according to how many more follow-ups I need. So, you know what? We're going to skip this follow-up or we're going to skip the last three treatments because I'm feeling better, and it is actually better for my family and better for us psychologically if we don't have to keep travelling back to the city."

The Hon. WALT SECORD: Would this be a handful? Would it be dozens?

Ms MILLER: No, it is a very regular thing we hear. I also like to point out that there are many people on clinical trials nowadays, which are actually part of normal treatment. IPTAAS does not cover clinical trials, so there are a lot of decisions that people have to make. Often, depending on their cancer treatment and their type, they are offered a clinical trial, which may actually really benefit them, but because IPTAAS does not cover any travel and accommodation for clinical trials, they may make the decision that they are not going to try it. They may or may not speak with their family and make that decision, that "we can't really afford it because what if the trial doesn’t work? We can't afford that." As we said in our opening statement, it then becomes a postcode lottery.

The Hon. WALT SECORD: How do you support people who, because of cost, decide not to pursue treatment? What support do they receive and how can they be supported, and what happens to them?

Ms MILLER: The ones we can support, that actually are willing to take our support, we can support them with travel and accommodation costs. We can support them with emergency financial assistance to pay some of their bills. We can support them with financial counselling to balance their budget and to look at how they can proceed with what they do have. We can support them with—in a pro bono area of financial and legal assistance, so we can prepare wills, we can look into their superannuation, we can investigate insurance options. We provide psychosocial support through our information and support line, counselling for them and their families, peer supports, so a wide breadth of information and support. What we absolutely want to do is support everyone we can to get to cancer treatment.

The Hon. WALT SECORD: Thank you.

The CHAIR: That is most helpful evidence. We will now proceed with questions from the crossbench. I invite Deputy Chair the Hon. Emma Hurst.

The Hon. EMMA HURST: Ms Phillips, in your opening statement you mentioned that there was a four-week wait for many people to see a doctor. You also talked about the stretch for social workers. What are the waiting lists looking like to get a social worker to assist?

Ms PHILLIPS: You may never even get a social worker being in touch with you. They are only working on points of a headcount, so we are not talking a full-time equivalent. Social workers—the ones that we talk to—are stretched from first cancer diagnosis all the way through to palliative care. They are dealing with the real emergency triage, so there are some people that may not even get to see a social worker. That is where our volunteers are coming in, trying to direct them with some information of just where to go and who can help. It is such a lack. From the time I came into this role, our volunteers have cried out to say there are not enough social workers across the State. The more we dig into it, their caseloads are just way too high. They don't see the numbers in their communities.

The Hon. EMMA HURST: Yes. In your submission you also talked about—or certainly it seems like there are a lot of community charities that are having to fill in the gaps and to help pay for things like transport and accommodation. We have heard from other witnesses who have come before this inquiry that they are really stretched, particularly at the moment because it is harder to fundraise for these things because of COVID and bushfires. Is that something that you are experiencing as well? Is it fair that charities are having to fill some of these gaps? What needs to be funded?

Ms PHILLIPS: It certainly is not fair. I think why Can Assist resonates so strongly in rural New South Wales is that rural communities are a bit tired of having money leave the community. I think we really resonate because they see their local money helping their local own, so they step out. Yes, our revenue has been down during COVID, but we have still had an immense amount of support because I think that is what the charity stands for. It is about getting people this access, and they also know in their communities that they do not have that access. But you go to the extent—no, I touched on we are in joint venture with Cancer Council down in Wagga Wagga. There are these not-for-profit organisations that are keeping their doors open from donations, from working to get grants, relying on—really IPTAAS has to keep those doors open, and it should not be down to communities to be able to provide affordable accommodation for people who need to get to hospital. It really should not be down to the charities, but thank God we have our volunteers.

The Hon. EMMA HURST: Yes, absolutely. Mr Mitchell and Ms Miller, in your submission you talked about it being more cost effective to invest more in preventative healthcare measures. That is something I am quite passionate about. My background is in health psychology and we looked a lot at prevention, and obviously there is very little funding in the prevention space. What health programs do you think would be most useful and should get more investment in the preventative space?

Mr MITCHELL: Perhaps I will pick that up, Ms Miller, and you might want to follow. There is no question that investment in prevention is a very worthwhile investment—it's obvious—and it takes many forms. Prevention campaigns at the State level and, indeed, at the Federal level are important, and both, in our view, have been underfunded for a lengthy period of time. If you take, in the case of tobacco, still the largest killer when it comes and the most preventable in terms of cancer harm et cetera, anti-smoking or anti-tobacco prevention campaigns have been underfunded for years and years—many, many years, as I say, at the State and Federal level, whether it goes to sun protection, whether it goes to nutrition, and then, of course, there is the national screening programs. So prevention is important but so is screening and early detection. The earlier we can find cancer is really, really important.

If I could tack on just to support and reinforce the comments Ms Phillips made about charities and costs, particularly living through COVID, we are a large charity and very well supported. Fundraising is really challenging. It is challenging right across the economy at the moment for all charities, I think. Our revenues are down in fundraising—it fluctuates between 20 per cent and 30 per cent—so that is challenging on that side. But I think the important thing for us all to note is that we know that demand for our services—this is all parts but certainly across Cancer Council—is only going one way. I mentioned about the potential surge in cancer diagnoses and also more serious diagnoses because of the likelihood of advanced cancers because of the delay. We know that the surge is going to affect demand for our services and, frankly, our ability to continue to fund it year after year after year is going to be a significant challenge, so the Government clearly has a role to play here as well.

The Hon. EMMA HURST: Absolutely.

Ms PHILLIPS: Could I just—

The CHAIR: Thank you very much.

Ms PHILLIPS: Sorry.

The CHAIR: Please proceed, Ms Phillips.

Ms PHILLIPS: I just wanted to add on to what Mr Mitchell said too. I think a lot of us always think that it is the down-and-outs who put their hand out for help too, but I really want to table that the expense is across the spectrum. You could have someone that you think is asset and cash rich but behind the doors they are not. They are also calling out, and they can fall through the cracks. So it is not just those people who we means test; it is a real spectrum of people that need help when it comes to a cancer diagnosis when you live in the bush.

The CHAIR: Thank you very much.

Ms GALLAGHER: Could I add one thing too, just in relation to the comments around social workers. At Tamworth Hospital, for instance, the social workers there get 20 referrals a week. They only get to half and, as Ms Phillips said, the 20 referrals that they get are the people who are really in trouble. There would be a whole lot of other people who are just never eligible for that service.

The CHAIR: Thanks, Ms Gallagher, that is a very helpful piece of information. Cate Faehrmann?

Ms CATE FAEHRMANN: Just keeping on this train of questioning, here in Australia we have Medicare and public hospitals, and there is always a sense that you can get treatment if you need it because we are in Australia. We do not have a US-style healthcare system, but what you are all talking about in your submissions sounds like that is almost what it is. Where people are sick, they need treatment. They are going to die if they do not get treatment. I think the stats say 20 per cent of people are choosing not to get treatment. It is kind of alarming. We have another submission here that says by 2040, I think, 88 per cent of people in regional New South Wales will be over 65, so something really big has to happen in the next 20 years if people are already refusing or, sorry, cannot get treatment because of costs. Ms Phillips, I might go to you first to get a response on that.

Ms PHILLIPS: First of all, even before you talk about costs, it is actually just access—to get a doctor—and that is just having a doctor on the ground and the support systems there; put the cost aside. Then you start going down—a lot of people do not even appreciate the costs until they are on this journey. It is then having to—again put cost aside—it is leaving home, commuting, accommodation. It is all that other layer of just being overwhelmed when you get hit and being told that you've got cancer. I like to think that once people come in and get that treatment and that access, we are there to get you the access, no matter where it takes you, but then you do start on this journey. No one cancer diagnosis seems to have the same dollar value against it. I cannot sit here to tell you today and say that if you get breast cancer this is what it is going to cost you because it depends where you go, who you see—public, private—where you live. That is where this is just—it is great you guys are listening but it is a bevy of different cuts that we can give you.

Ms CATE FAEHRMANN: Ms Miller, do you have a comment on that one as well?

Ms MILLER: Yes, I do, thank you very much. I would like to point out that treatment for cancer has become amazing. We should not forget where we have come from just in the last couple of years, but the system is not keeping up with it. So if you are diagnosed with a specific cancer where we know that a type of treatment is absolutely optimal and it is in a certain area, then that is what is recommended to someone. But for the layperson, when you go in and get diagnosed with cancer, the first thing you are going to think about is how much is this going to cost, if you are living rurally, and how can I get access. And then, everything else, your brain shuts down so you cannot actually even put the dots together.

I think the systems we've got, whilst we have touched on the fact that the outcomes in many cancers are fantastic, there is a disconnect between public and private. There is also a disconnect—and we hear from oncologists when they refer someone on or a GP who may refer someone on to an oncologist, that GP or that specialist will often not communicate with their colleagues as to how much that is going to cost someone. So it is very clear—in the clinical oncology conference late last year, there was a great amount of discussion about financial costs, and what was quite incredible was an oncologist would say, "I'm referring them on to have radiology, but I have never actually asked what that could cost," so the person does not know about what they might be out of pocket for. So we would really recommend that everyone, every medical professional, signs on to use the informed financial consent. That is so important up front to sit down with the patient to discuss what their costs are going to be, and that is not happening very much.

Ms CATE FAEHRMANN: Thank you. It is extraordinary, actually, that it is not happening—that something that basic is not happening. Just quickly, I probably have time for one last question.

The CHAIR: Yes, sure.

Ms CATE FAEHRMANN: I want to ask Cancer Council NSW—sorry, I have just lost sight of my screen. Mr Mitchell, the first recommendation in your very comprehensive submission was "implement and embed the Optimal Care Pathways". I understand from your submission that it looks like Victoria has signed up to this but New South Wales has not. Could you explain to the Committee a little bit about why we need to sign up to Optimal Care Pathways, what that incorporates, and why New South Wales has not signed up to it? What is the history of that?

Mr MITCHELL: I would have to take the last part of your question either on notice or perhaps ask Annie Miller if she can elaborate, but in terms of the nub of the issue around providing patients with optimal care—so, Optimal Care Pathways, there is a huge amount of evidence and research that go into how should you approach care, how should you provide care and how can that be made clear to patients. We are involved, along with other organisations, in coming up with Optimal Care Pathways. As to why they have not been adopted or followed in New South Wales, I would ask Annie if she can throw light on that, but otherwise I would have to take it on notice.

Ms MILLER: Thanks, Jeff. That's a great question. I think we will take part of this question on notice, but I can say I think it is the way, in New South Wales, our health system is set up. We do not have a framework that is overarching for all of the treatment centres, so it is very definitely a decision that is made by local government area and a treatment centre as to whether or not these will be embedded. We really advocate that they are, but our system is very different from Victoria.

The CHAIR: Thank you, Ms Miller.

Ms GALLAGHER: Chair, sorry, excuse me. Could I just make a comment back on the prior issues around people skipping treatment?

The CHAIR: Sure.

Ms GALLAGHER: I just think that it is a multifaceted approach, there are lots of issues involved, but it has got to start with a better IPTAAS because if people know right from the stage they get diagnosed that this scheme exists—if you look at that survey that we have conducted across our branches, across six local health districts [LHDs], across all of our accommodation providers, you are talking about 60 per cent of people who do not know about it, and then, once they get it, you are talking about 90 per cent of people, no matter where they are, that need help filling out the forms. I think that that is a very practical thing that needs to be done, and there needs to be budget allocated towards that, not only to lift the rates but to increase the awareness of the scheme and to make the form and the process far less complex. As Mr Mitchell was saying before, widen the eligibility. That could make a very real, very quick difference.

The CHAIR: Thank you, Ms Gallagher. I turn to the Hon. Wes Fang. I appreciate there have been some lengthy responses. I will provide you with additional time so we do not crimp your 10 minutes.

The Hon. WES FANG: Thank you, Chair. To be honest, I think a lot of the questions that I was preparing to ask have been asked by other members—

The CHAIR: You take your time.

The Hon. WES FANG: —so I will probably not use all of my time. First, I want to start by thanking both of the organisations. I have had numerous engagements with both of you in a number of factors: Obviously, in a professional role, but also my father, who passed away from cancer in Wagga a number of years ago, was very well supported by a number of organisations. So I have had a lived experience, shall we say, with dealing with cancer in a regional setting. I very much thank both of the organisations for the work that they do. One of the things that I find interesting is the IPTAAS issue, and I say this as someone who does live in the regions and who has multiple children who have had to travel for medical help, but also as somebody who has a family background in medicine. Even with our experience we struggle with navigating the IPTAAS form and the issues.

From your perspective, what do you think we can do around applications for grants from IPTAAS to make it simpler and easier for people to access and understand what it is, how to get it, and that it is actually there. I will start with Can Assist and then we will move to the Cancer Council.

Ms GALLAGHER: We have done, as I mentioned before, some surveys on it. I think, at the very basic, you need to have a more simplified form. If you are a patient in rural Australia that has to see a specialist more than once and you stay in one of our accommodation facilities, you have got to fill in 11 pages worth of forms. If you look at the VPTAS form, which is the Victorian Patient Transport Assistance Scheme, you only have to fill in three pages and then, when you look at the forms, we need double the amount of signatures of a place like Victoria, and often the initial signatures that you need, you do not find out about them until you are halfway through the process. So we actually have our volunteers running around to local GPs trying to get referral signatures. Seventy-eight-year-old Margaret from Tumut is doing 10 of these a week, and it is a similar story.

So my first comment would be get rid of the referral signature. Victoria doesn't need it; we don’t need it. Then you need to simplify the forms. There is so much repetition. It is so overwhelming for people. Also, the terms are not explained; like, what is an authorised representative? That is who's got to sign it. Nobody knows who that is, so they are getting the specialist to sign it when really they don't need the specialist. Then there are things like this 200-kilometre cumulative rule that you are probably aware of: that if you clock up that with multiple trips, you are eligible. That is not on the form, so nobody knows about it. It breaks our heart. We are telling these people all the time, "Apply! You're eligible." Then there is confusion about what specialists you can apply for, escorts.

I could go on and on, but we would love to—our proposition to NSW Health is to sit down with a working group of people like us, like social workers, like patients—people who use these forms—because the last time they changed them in 2017 they had form experts in but they did not bring the stakeholders in. I think that would do it. If it was an easier process, it would promote itself. And then there is—I could go on, but it needs to be promoted. IPTAAS have a lot of good data out there. They know who's using it; they know who isn't. We should look at that data and work out who do we need to tell and how do we need to do it, and then we need to be monitored and evaluated on whether that is working, rather than just saying, "We spent $25 million last year. It's working." That is not a benchmark.

The Hon. WALT SECORD: Ms Gallagher, would you agree that would be a good recommendation?

Ms GALLAGHER: Absolutely. We need more budget to do this stuff because everything costs money.

The Hon. WES FANG: Chair, that was pretty much all I wanted to address. We can delve into how we can get more services into the bush, but I think those are wider and more complex issues. To the point that both organisations have raised, that access to IPTAAS will make a huge difference to not only cancer patients but, I think, all rural and regional people accessing medical treatment. If there is one thing that this Committee can do to assist, it will be to simplify that IPTAAS process. I think we can address a lot of the other questions in further hearings or through questions on notice at some other point, but I think both organisations have helped to address IPTAAS and highlight the importance and how to simplify it. Noting my time has almost expired and that we are due to finish shortly, I thank the organisations for raising such an important issue.

Ms MILLER: Could I—

Mr MITCHELL: Chair, could I just add, if I may, just briefly on IPTAAS?

Ms MILLER: Sorry.

The CHAIR: Yes, please.

Mr MITCHELL: I support the comments made but, as a government that wants to take care of the community, you really need to step back from this and think about why are there so many checks and balances and signatures and complexity put around a system that was put there with the intention of helping people who need the help? It is not only the paucity of the assistance when you look at—one of the pieces that we looked at is if you are a New South Wales Government employee you are rightly reimbursed for travel, currently at the Australian Taxation Office rate, which is 72c per kilometre. IPTAAS is currently 22c per kilometre. That disparity should shock us, but the overriding point around accessibility, simplicity, that comes from what is the intent. So I think, as was suggested, sitting down with the people who use these forms, organisations like Can Assist and Cancer Council, social workers, treatment centres et cetera, and completely redesign it so that it achieves its purpose, which is to assist people who need the help to get to treatment.

The CHAIR: That is a very fair point, Mr Mitchell. It has obviously been made and clearly underlined, and I am sure the Committee members will be looking very closely at that. I take this opportunity to thank you all for participating today. Speaking for myself, but I am sure for all the Committee members, it has been very fruitful, hearing directly from two organisations that are undoubtedly known as premier organisations in this State, particularly in the context of the work done through their volunteers. The good that you do for citizens of this State who reside both inside and outside the metropolitan areas is incalculable. We thank you all very much and ask you to pass our best wishes on to the officers, staff, volunteers and supporters because without that collective contribution we would be a much poorer State. There is no question about that. We have gone a little over time, so it will be a quick transition to our next witness.

(The witnesses withdrew.)

(Short adjournment)

RUTH ARNOLD, Rural Co-Chair, New South Wales Medical Staff Executive Council, affirmed and examined

The CHAIR: I welcome our next witness to this public inquiry, Dr Ruth Arnold, OAM. All the audio issues have now been resolved and the Committee is very much looking forward to hearing from you. The submission from the New South Wales Medical Staff Executive Council was very helpful. I presume you have had some involvement in its development, if not a significant amount of involvement. I confirm that the submission has been received by the Committee and stands as submission number 276. It has been received, processed and stands as evidence to the inquiry. We thank you and the executive council very much for that, which you can take as read. All Committee members have a copy, will have read it and no doubt will have some questions for you. I commence by inviting you to make an opening statement. If you are agreeable, we will then move to questions, which will be shared among the Committee members, to take us through the duration of your time this morning.

Dr ARNOLD: Thank you very much for the invitation. Firstly, the opening statement. By way of introduction, the New South Wales Medical Staff Executive Council [NSW MSEC] is formed of the Medical Staff Council chairs of all New South Wales public hospitals. These are the elected representatives of all senior medical staff employed at public hospitals. Input for this inquiry has been provided from senior doctors across New South Wales with decades of experience within the public hospital system. It is the sincere hope of the NSW MSEC that the current parliamentary inquiry will be able to synthesise all the material it receives and make robust recommendations for comprehensive, bipartisan reforms of key areas of the New South Wales healthcare system. Providing equitable access to high-quality health care for regional and rural patients requires a fundamental change in philosophy in how New South Wales chooses to structure and deliver healthcare services. It requires a change to the current structures to create a truly statewide model aimed at ensuring equity of access and uniformity of healthcare standards.

The problems that exist in the delivery of regional and rural healthcare have been well documented. The fact that there are problems with staffing, resourcing and health outcomes is well established. The follow-through of effective, coordinated reforms has been deficient to date. Improvements can be achieved. When large, ambitious, clinical improvement programs are funded and coordinated at a statewide level, such as the regional and rural cardiac catheter lab and reperfusion strategy between NSW Ambulance and Health, big gains can be improved, so it can be done. However, a statewide focus needs to be applied to many other areas.

In essence, the keys to making a big difference in rural healthcare delivery need to focus on delivering key structural reforms in 10 key areas, which I will summarise briefly. Re-establishment of statewide services planning, rather than a reliance on the current silo LHD model. In general, rural hubs for almost all services can and should be established as the metro-centric model is not cost effective. Highly intensive subspecialised services need robust services to ensure equity of access, such as paediatric intensive care. Number two, reform the independent oversight and governance structures. The Auditor-General's report covered this and made recommendations in 2019. Number three, establish avenues for early conflict resolution which are independent of the LHDs. In particular, in cases where a Medical Staff Council votes "no confidence" in a hospital and/or LHD administration, an automatic and comprehensive review, independent of that LHD, must take place by external agencies.

Number four, review the role and performance of the LHD boards. These are intended as an oversight body, distanced from the Chief Executive. This has not always been the case. The Auditor-General noted a lack of clarity on what is operational and what is strategic, and noted a need for formal board orientation and education, and some boards see themselves as "rubber stampers", which may reflect the reality and the deficiency of the current LHD boards as strategic oversight bodies. Number five, fix the poor engagement of boards with clinicians and poor inclusion of clinicians in decision-making, and set the key performance indicators [KPIs] around that.

Number six, stop the overspending of public money on consultant reports, which was $29 million in 2020, and reinvest this money. By consulting clinicians within the organisation or within the pillars, that could build resources and strategic planning in house. Seven, take the huge wealth of data that we are currently generating and use it to improve systems. Eight, address the specialist workforce distribution at a statewide level. The myth that current deficits in per capita specialists in regional and rural areas is due to specialists not wanting to go rural must be dispelled. It should be understood that obtaining approval to fund a new position can take years of business cases and lobbying, and leaving workforce decisions solely in the hands of LHD finances is a poor system that does not take a statewide vision on workforce distribution.

Number nine, ensure stable referral pathways for the transfer of regional and rural patients to hub and metro hospitals and establish KPIs on waiting times. Ten, ensure that any rural health solutions for telehealth meet short-, medium- and long-term needs of regional and rural patients, and that they support and communicate with locally based clinicians and do not seek to replace them. That is a summary of where we find the key areas and the ways forward, but I am more than happy to take any questions about any content of our submissions or any of the areas where we think reform is key.

The CHAIR: Thank you. Before we commence I acknowledge the enormous contribution that you have made in your own right, noting that you commenced as a cardiologist in Orange in 2001, which is 20 years ago, and that you bring such knowledge, experience and insights forward to enable us to ask you questions. We thank you for making your time available from what is obviously a very busy schedule.

Dr ARNOLD: Thank you.

The CHAIR: We commence with the Hon. Walt Secord.

The Hon. WALT SECORD: Thank you, Dr Arnold. I go to one of your recommendations where you talk about early conflict resolution. We have had evidence to this inquiry that doctors who see faults or problems in the health system in rural and regional areas fear retribution from NSW Health and the Government. As Rural Co-Chair of the New South Wales Medical Staff Executive Council, do you get reports of people wanting to make recommendations or highlight deficiencies who are fearful of retribution from NSW Health?

Dr ARNOLD: Absolutely the current system does not make this easy when people need to raise concerns. The problems are that there is a tendency for staff to raise concerns, administrators to defend their position because they do not want to admit that they are wrong or that there is blame. That situation needs to be diffused so that the focus can be on patient care and on quality and on sifting through what are genuine concerns about how the systems are running, and getting away from the self-defending stance of some administrators. Then you have processes whereby NSW Health does not always have the jurisdiction in the current model, nor the resources, to look into everything in as much detail as they could and should. They rely on the input from the LHD. They ask the LHD, "What's all this about?" The LHD can tell NSW Health what they like and that everything is okay, which is not always the case, and the resources to independently step in and arbitrate are deficient and lacking.

Sometimes that can escalate to horrible degrees. There have been cases where local health districts have had clinicians trying to raise concerns about deaths that should not have occurred that have not been reported to the Coroner, and about major systemic problems such as in Broken Hill. It took a long time for those doctors to manage to get anywhere, to get any traction outside of their LHD and to have those concerns investigated. There was a report done and multiple recommendations made, and yet the local health district that had overseen some of the problems in the first place was then charged with the implementation of these reforms.

This is a system that does not work well on behalf of patients or concerned clinicians within the organisation. There needs to be a better, less adversarial way to fix it. I would recommend that—the Garling pillars were meant to have more resources than they had; they were meant to be able to perform some of this role. I was on the panel to oversee the Garling recommendations and the implementation of those left out key facets. Leaving out key facets of a recipe is like cooking a cake without the baking powder: It is going to be a flop, okay? If you do not have the correct audit structures and the correct accountability, you create these problems. So yes, staff fear retribution and it is a problem.

The Hon. WALT SECORD: Do you find that, in fact, rather than concentrating on fixing the problem or improving health care, there is more of an interest in defending the situation or refuting the doctor making the allegation than actually trying to fix the problem?

Dr ARNOLD: Absolutely, absolutely. There is a defensive stance, there is a cover-up mentality, there is a "keep things out of the media at all costs". But there are some fantastic people in NSW Health who, when they do step in with sufficient resources, can analyse and sort through what is true, what is not. But there needs to be avenues where people who can give proper input to these very serious situations can do so in a more timely way. The doctors and nurses who raise concerns about their patients, about patient care and about administrators who in some cases are simply not even following mandated NSW Health policies and procedures should not have to go through the hard processes that it takes to raise these concerns.

There should be given standards of administrative performance, and if they are suboptimally performing, there should be not a defence of their actions at all costs; there should be a genuine analysis and a way of fixing that. I think the problem becomes—if there is an admission of guilt, there are a number of facets. Often if you admit guilt, apologise for something, analyse it and fix it and move on, which is what we are used to doing as clinicians—if health care is not optimal in every case, that is what we do all the time—we need to take that approach to take the heat out of the problems when there is an administrative issue. You need to be able to say, "Okay, that was not right. We can do better. This is our plan moving forward." Take the adversarial nature out of it.

The Hon. WALT SECORD: Dr Arnold, we have heard repeatedly across the State that there are emergency departments [EDs] in rural hospitals where nurses end up being the only line of health care in those hospitals and doctors do not want to work in those emergency departments. Now, we want to make tangible recommendations. How do we get doctors in emergency departments in these rural and regional areas? What is the barrier to this occurring?

Dr ARNOLD: There are many facets and different solutions for different locations. There are different levels of hospital. There are certain levels of hospital, which I believe you have to staff, and there are some whereby you can utilise healthcare resources wisely and still provide a service. Let's just take a look, for instance, using the vast area of Western NSW Local Health District as an example. If you have no doctor in a remote facility but you have a nurse, you can manage even very unstable patients if you have to do with phone backup, with ambulance service backup. There is a program called Clinical Emergency Response Systems Assist, whereby paramedics can come into the healthcare facility to assist nursing staff to stable a patient for immediate transfer. You can have critical-care experienced doctors and emergency physicians and cardiologists on the phone even via video link to assist that process.

Is it better if doctors can be obtained to staff all of these areas? Yes, but if that is not available I think you need to look at, "Are the resources of nursing staffing adequate and are the resources of paramedics and ambulance staffing adequate to all of these areas?" because these are valuable avenues where there are more staff easily able to be obtained who can make a massive difference to patient care and deliver a quality service. In terms of doctors, sometimes the very small sites can struggle to find permanent workforce. There needs to be a focus on supporting and making those jobs attractive so that there is a permanent workforce in those areas to follow through and provide long-term care for patients. You will not always be able to staff emergency departments with local people because no doctor can do one in one on call, even one in two—it is not rational. You need a support structure that utilises all healthcare professionals in your model.

The Hon. WALT SECORD: Dr Ruth, we have had evidence of doctors working extraordinary hours per week—between 60 to 90 hours a week. Are those doctors in rural areas just outliers or is that something that you hear quite commonly, that doctors are working extraordinary hours in rural and regional areas?

Dr ARNOLD: Sixty to 90 hours?

The Hon. WALT SECORD: Yes.

Dr ARNOLD: So that is five 12-hour days? Yes, that is pretty normal.

The Hon. WALT SECORD: That is normal?

Dr ARNOLD: If rural and regional doctors have enormous demand for services, that would not be uncommon at all. A 40-hour week in medicine in rural does not exist.

The Hon. WALT SECORD: You have been in Orange now for 20 years. During that time do you provide cardiac advice to your nurses in remote and regional hospitals? Do you use telehealth?

Dr ARNOLD: Absolutely. We run a centralised ST-elevation myocardial infarction, or STEMI, service in Western NSW LHD, which covers a vast area of the entire State. It is an enormously successful program that has improved the heart health outcomes considerably. We have run that 24/7 service since about 2013 or 2014. We support paramedics in the field with direct phone calls to paramedics who are caring for patients having heart attacks in the back of ambulances. We support nurses who have got no onsite backup in small hospitals. The key to the system is a networked approach and it feeds in to respectfully combine with the care provided in each of those settings by all healthcare professionals and doctors and it is a system that feeds back into follow-up locally. It is an excellent telehealth model. Telehealth can be an extremely useful, powerful tool, but it needs to be very carefully constructed.

The Hon. WALT SECORD: I understand that. Do you have situations with—we have had reports of the use of telehealth. Are there certain areas where you think telehealth should be a no-go area? Are there certain things that it is just impossible to replace a doctor with?

Dr ARNOLD: Yes. The cardiac services is the heart attack support program, that is one component that works well. The second component of telehealth—Western NSW LHD has run originally a service called the Critical Care Advisory Service and then moved to vCare, virtual care, and there were massive problems with the rollout of that particular model and numerous feedback of poor systems from specialists that were involved with the change. Now the keys and the differences in the change is that, in the first instance, it was run by locally-based consultants with skills in critical care or emergency medicine, so they were at a high level, they were locally based, so they had a fundamental respect and knowledge for the other clinicians working with the area and a knowledge of the towns and the people and the system and the infrastructure and the resources that they were dealing with.

You then had a shift to a model under the directorship of somebody not from the area, often employing people not from the area, and that program is still in the process of being improved because the fundamental problems were that if you put someone on those lines who only deals with the here and now for the patient, you do not focus on their medium- and long-term needs for healthcare follow-up and do not plug back into the local system and do not have an understanding of the local system—what is available—it is a disaster, potentially, for patients. Secondly, the staffing experience and the level of people who were then put on to that service were variable. Some of them were just simply not of an adequate medical standard.

The Hon. WALT SECORD: What do you mean—

The CHAIR: Thank you very much. Thank you, the Hon. Walt Secord. We will need to move on. We may have time at the end to come back. We now move to questions from the crossbench. Deputy Chair, the Hon. Emma Hurst.

The Hon. EMMA HURST: Thank you, Chair, and thank you, Dr Arnold, for coming in today. One of your key areas that you highlighted in your opening statement was around poor engagement from boards with clinicians. I want to know a little bit more information about what was actually happening on the board. What are the outcomes of that poor engagement and what does change actually look like as far as a recommendation within the inquiry?

Dr ARNOLD: Yes, medical engagement with senior doctors and nurses in how [audio malfunction] healthcare services is crucial to the team approach and building a robust service. The boards, I suppose, routinely engage with the chairs and medical staff councils and routinely invite them to every meeting. That does not always happen. Due to the current system where, even if the medical staff council chair attends, their rolling board meetings is limited, their input into, and ability to, influence key service delivery decisions is profoundly limited. There is no defined structural role about what input the medical staff do have, could have, should have in the structure. Often there is not a lot of point them turning up because they feel that they are barely involved if they do. There is a disengagement with that entire process.

The Auditor-General report acknowledged that the input into local decision-making had not been realised in this devolved model as well, so it is well recognised it is not functional. There were surveys across the State of all the MSC chairs that we conducted and is on our website, which demonstrated that many MSC chairs are never consulted and never invited and do not have any quality input. Look, it is a deficiency of the system because the key people who know what needs to be improved on the ground are your senior doctors and nurses. So what does it look like to reform it? I think routine inviting of senior doctors and nurses to board meetings, but actually giving them a voting role in service delivery and models of care so that it is worthwhile—their input and their time investment—in attending.

The Hon. EMMA HURST: I just want to also talk about a couple of things that you mentioned specifically in the submission. You note in the submission that the KPIs for LHDs are mostly about volume or time-frame based or focused on financial measures. But in order to improve those clinical outcomes the KPIs should be clinically based. Can you tell us a little bit more about that and just expand it for the benefit of the Committee?

Dr ARNOLD: Yes. There is a big focus, for instance, on emergency access times. That is important because if people go to an emergency department they want to be processed quickly. But "process" is a word. Are they processed and shuffled into a corner somewhere just to meet those targets—box ticked—without a thorough medical assessment that met their needs? Well, it is hard to capture that. You can capture that in terms of readmission rates to hospital and things like that, but we already collect a wealth of data. The Bureau of Health Information collects a lot of data on outcomes of clinical conditions—key outcomes like 30-day mortality for heart attack, stroke care, outcomes for people who brake their hip and how the systems are performing—and that data gets published and put on a website usually only every three years. But there is no real-time fix. There is no focus on that clinical data about how well a hospital system is treating heart attack, hip fractures or whatever, and putting a KPI around that and saying, "Well, you have not dealt with this very well. Your figure is as bad as they were three years ago," and having any financial repercussions or key inputs requiring them to implement best practice to improve those figures.

The focus is on, yes, emergency access and off-stretcher time, which is only one part of the equation; it is not how good is the quality of the service you are running and it is also not looking at other facets of the problem, such as, there are a lot of bed days in hospitals that are spent—wasted money—of patients waiting for transfer to another hospital for definitive care or waiting to get back again. If there is no KPI around that, then the hospital system gets clogged up with poor patients who are waiting for care that you are not measuring. There is no KPI around it because you are only focusing on getting people off ambulance stretchers. So if you do not look at the whole system in your analysis then I think you come up short in looking at where the problems lie and keeping the flow going right through the system in an economical way.

The Hon. EMMA HURST: Just on that point about transferring patients, I think you also said in your submission that the model of transferring regional and rural patients to metropolitan centres is more costly than actually investing in local care. Can you tell us a bit more about that and that costing?

Dr ARNOLD: Absolutely. NSW Health spends about $112 million per annum on transfers. You will not be able to save all of that, but you can save a lot of it. For instance, the rural catheter lab program is one that I am very familiar with. Prior to that program being rolled out under the former Statewide Services, which of course no longer exists, that program has shifted care of heart attack patients in the regions, remaining in the regions. Western deals with at least 80 per cent of its heart attack work and does all of the stents and the care that is required without transferring them to Sydney. Now, prior to having a cath lab in 2012 all of that work went to Sydney. That is about 400 patients a year, 80 per cent of whom are kept in-area. Without that 400 times $5,000 an ambulance ride, at least, that is quite a lot of money to invest in local services, local infrastructure and local jobs. These are cost shifts that not only benefit patients and give much better value care; they are cheaper, more effective and they give local jobs for regional and rural nurses and radiographers. It builds skills and it is a better investment for the future of New South Wales because you are spending more money on actual health care and less on transport and aircraft fuel—more money on patients.

The CHAIR: Dr Arnold, can I confirm that you would be, if you are able to do so, available for an extra 10 minutes until 12.15 p.m.?

Dr ARNOLD: Yes, certainly.

The CHAIR: That is wonderful. Thank you very much. We will move, then, to Cate Faehrmann.

Ms CATE FAEHRMANN: Thank you. I just wanted to go to your excellent submission. We have got a term of reference where we have to look at the analysis of the planning systems and projections that are used by NSW Health in determining provisions of health services. You have talked about the fact that the Statewide Services section of NSW Health was disbanded when the LHD system was set up and that as a result of that there is "no Department within the NSW Ministry of Health with the expertise or the brief to address the long term issues of poor access to medical care across the State in terms of rural and regional services." That is quite extraordinary. So there is nobody, there is no specialty or no department within NSW Health to address that? Is that correct, and it is just within each LHD?

Dr ARNOLD: Correct. This is a big problem. As I said to you, the Garling recommendations were rolled out with some key facets missing, and that creates the cake that is a flop. The Agency for Clinical Innovation [ACI] was envisaged to be the body that would define what is best practice care, what are new innovations in health care and what the standards should be across the entire State. Now, the Agency for Clinical Innovation has some fantastic people in it, but it is under-resourced. You see, it was meant to come with the resources of access, ready access, to people with skills in business cases, cost analysis, people with skills in change management to roll out programs across the State.

These resources were never made available to the ACI and therefore it has not really ever been able to take on the role that the former Statewide Services, under Kathy Meleady, had in establishing where the services are needed. "You need hub services for cancer care in these locations," you know, "here they are—here are the resources to match and here is the change management that goes with that" that tells the local administrator, "This is what you are doing, this is what looks like best practice and this is how it is going to be run." The ACI could and should be the pillar that is tasked with this, but it has to have the extra ingredients and resources available to it to do so. That money could easily come out of the $29 million that is currently spent per annum on often useless reports from an external consultancy. That is a lot of money that could be invested into this strategic role within the pillars. There is a lot more that can be done in this space.

Ms CATE FAEHRMANN: Do you also have a view, then, about the amount of funding that has been put into new hospitals in some regional centres compared to, for example, the lack of resources into the ACI?

Dr ARNOLD: Rural hospitals have been terribly under-resourced in terms of infrastructure and running costs. Sometimes that investment in rural infrastructure has been necessary, but the infrastructure is one thing. There have been cases whereby the infrastructure has been present, but the commissioning of it and the ability to staff and run it has lagged a number of years behind the provision of the infrastructure. The opening of the Wagga cardiac catheter lab would be one example. Once again I keep using the cardiac examples because I know them best, but the infrastructure exists in those key locations ready to serve patients. However, most of the rural cath labs are not resourced or permitted to run 24/7. You have got patients who have got a cath lab in their local health district but it does not run after hours, so they are still transferred out of area. Well, that is just not good for patient care. The resourcing to say to those cath labs, "You know what, the facility is here; you need to run it and treat patients 24/7," that decision rests with the LHD. It is not a State-based decision that says, "Every patient should have access to 24/7 heart attack care." It is left to the LHDs about how they run and resource that.

To get the Orange cath lab open 24/7 took us years of business cases and banging our head against a brick wall. It takes sometimes a massive amount of effort from the clinicians on the ground to keep persisting and advocating on behalf of their patients and their communities to get these services to a level where they should be. Sometimes the business cases are there. You do not have the resources yourself to do the business cases and that should indeed be provided from people with the appropriate management skills. The local health districts in regional and rural areas do not always have resources of experience to manage it. We have had numerous managers through Orange of varying experience, and some of them with no health experience, so you kind of have to reinvent the wheel each time the business managers change. There simply should be a better statewide system that says this is what is cost effective, this is best care and this is what we are doing.

Ms CATE FAEHRMANN: Thank you, Chair. If I could just add one last quick question?

The CHAIR: Certainly, Cate.

Ms CATE FAEHRMANN: This is due I think again to what you have got in your submission. Because the LHDs are meeting KPIs that are all budgetary and are operating under budgetary constraints, therefore, for example, a 24/7 cath lab just look at it in terms of the fact that they have to meet KPIs around budget rather than demand. Is that what is going on in regional New South Wales?

Dr ARNOLD: Yes. They see a tight budget, but this is why I said some of these budget decisions need to be at a statewide level because they focus on their budget, okay? So by not running that service 24/7 there is huge extra money—400 times $5,000, so $2 million—in additional costs to transportation of those patients and to caring for them in other locations, not to mention the costs to the patients and their families just travelling out of area. That cost is not on the LHD budget, so they do not necessarily care about that. If you are looking at a statewide spending and the whole of the taxpayers' dollars, well, that makes no sense. Sometimes with the small amount of investment you could run a whole lot of cardiac catheter services for the cost savings in the transport costs. Those are the arguments that sometimes get over the line, but if it is not on the same balance sheet then they do not always go for those fairly obvious solutions when you are looking at money that is coming out of a statewide budget.

The CHAIR: Thank you very much, Dr Arnold. The Hon. Wes Fang.

The Hon. WES FANG: Thank you, Chair, and apologies for the lighting—it's the sun; it's not a halo. I just wanted to touch on the telehealth services that have been raised already during this inquiry. What we found is that there has been a lot of demonisation of telehealth and a lot of political games, I will say. But we were supposed to be in Wagga today and part of the reason that I was very keen for this inquiry to go to Wagga is to have a look at things like the Telestroke program where, if there is a patient having a stroke in a rural or regional area, they can get that advice from stroke specialists, and the outcomes have been very good. Are you able to provide some positive feedback on how telehealth has provided some positive outcomes for patients in rural and regional communities?

Dr ARNOLD: Absolutely. As I said, the telehealth cardiac program, which helps to treat heart attacks by beaming electrocardiograms [ECGs] and connecting key people caring for patients with consultant cardiologists and emergency physicians—that networked approach is powerful and makes an enormous difference to improving outcomes. The telehealth program for stroke is also an enormously powerful tool whereby you can have a video link set up and have an expert brought to the bedside. These are all powerful tools and excellent programs that can achieve big gains, but those programs link with local clinicians. They do not replace them; they are bringing a specialist to the bedside. They are bringing specialist care over the top of basic healthcare services. You have still got doctors and nurses and paramedics caring for those patients. You are bringing additional assistance to those clinicians and helping them care for patients.

Where telehealth can be quite rightly criticised is, you cannot replace always a hands-on approach and there are certain things telehealth cannot do. Telehealth must link with local clinicians. It has got to provide structure for ongoing care and ongoing assessment. I think where it has fallen down and can be rightly criticised is when assessments are poor, where the consultants giving the advice may not have had adequate experience or adequate ability to assess the information, or instances where there have not been arrangements for follow-up, there have been some terrible examples and mistakes made in cardiac care with patients sent home with inadequate assessments and no follow-up arrangements that we have had to pick up within our area because we monitor it, we watch it to a degree because we have the ECG service.

If we can see an ECG that has not been dealt with appropriately, we have got some avenue, but not routine checking steps to say, "Is that service fit for purpose? Is it performing well?" So telehealth is an amazingly powerful, a fantastic tool that can bring a specialist into a patient's bedside and use technology to its best advantage, but in a role and a model that supports clinicians on the ground and that provides a whole-of-patient care model into the future. That is where it is key. I think a sloppy service where someone wants to sit on a beach somewhere and provide ad hoc advice without a connection and an understanding of a rural location is a poor model, and depending on their level of expertise and whether the presence of that service blocks the recruitment of on-the-ground clinical staff—that is where I think you have to juggle the model and make it what it needs to be, which is bringing additional resources to the patient.

The Hon. WES FANG: Do you agree, though, that, in demonising the work of telehealth, what perhaps we are doing is losing the ability to give confidence to patients that perhaps are in rural and regional areas that may be, for example, experiencing a stroke or a cardiac situation, and a clinician or a senior nurse in a multipurpose service or a rural hospital may say, "I am going to get the telehealth doctor on," as an indication that they are going to connect to Telestroke or a cardiac service, and all of a sudden they hear the word "telehealth" and the patient has a concern because of the negative connotations, which have been progressed by people with political motives? Does that create an issue for us? Do you think we should be very careful about how it is that we talk about telehealth and not lose the benefits that we can get from the service by trying to politicise the issue?

Dr ARNOLD: I think a patient that experiences a well-performing healthcare model does not usually have a problem with the delivery of that model. I have certainly not come across patients who have had problems with the involvement of clinicians via video or telehealth link. But I guess in our model those patients are almost always seen by the clinicians involved as part of their episode of care, so it is a tool that allows the outreach to them quicker, but then they still see a doctor. You need to make telehealth services excellent and then any bad reputation around them will be diminished. They have to feed into on-the-ground services. You cannot replace with video the examination of a patient. In COVID we have done a lot more telehealth, and there are some things that you can do via a telephone, some that you can do via video, but some that, at the end of the day, you have to do in person.

You can only stave off even seeing relatively stable patients for so long until somebody, be it doctor or nurse or clinician, must examine them properly because you cannot pick up all things on a video link. Things get missed. So it is a powerful tool but it has to be structured well, and that is still a work in progress. I think a lot of these technologies are relatively new and their power and their role in medicine is still being defined, but definitely, definitely do not throw the baby out with the bathwater because telehealth, as I said, is a powerful way to make a massive difference in some conditions and to bring specialist care into regional and rural areas more comprehensively and at an earlier level, which can make a big difference.

The Hon. WES FANG: Thank you very much for your insights. I note my time has pretty much expired. I really do value the experience you have brought and what you have been able to provide via testimony today. Thank you very much for providing some balance to the telehealth system.

Dr ARNOLD: Thank you.

The Hon. WALT SECORD: Mr Chair, I understand there is about 30 seconds left. Can I just clarify something that the Hon. Wes Fang has said? The evidence that we had, concerns about telehealth, came from nurses on the front line rather than patients, so I just wanted to correct that. That was nurses that expressed concern about telehealth. Thank you.

The CHAIR: I will take that as a comment, I suppose.

The Hon. WES FANG: I was going to say, Chair, I could raise a point of order that really it should be a question directed to a witness but, by all means, the Hon. Walt Secord is very good at making noncompliant contributions to the debate.

The CHAIR: Thank you. He probably would say to that that he has learned from the master, so we will leave that there for the moment. Dr Arnold, on behalf of the Committee I thank you very much for making your time available today. We know that you are exceedingly busy, but we thank you for your tireless work, the research that you undertake and the very forthright and strong advocacy that you bring to the discussions around what we all want to do. I do not think there is any question around the Committee table—it does not matter what party we are from—we all want to see what might be the ways and means that we can as a State raise and improve the health and the wellbeing of the citizens who live outside the big and the large metropolitan areas. Thank you all very much.

(The witness withdrew.)

(Luncheon adjournment)

PETER MALOUF, Executive Director of Operations, Aboriginal Health and Medical Research Council of New South Wales, affirmed and examined

MARGARET CASHMAN, Director of Ethics, Policy and Research, Aboriginal Health and Medical Research Council of New South Wales, affirmed and examined

The CHAIR: We welcome our first witnesses for this afternoon. On behalf of the Committee I thank you both very much for making yourselves available this afternoon. We know you are very busy with your various commitments. It is a privilege to have you both this afternoon being able to provide us with some [audio malfunction] inquiry. Can I confirm that, with respect to the submission that has been made, the submission has been forwarded, as you would be aware, to the Committee secretariat. It has been processed and the submission stands as submission No. 265 to this inquiry. It has been processed, uploaded onto the webpage of the inquiry and obviously is there for people to study. That is evidence, which is very helpful for our inquiry, but we now have the public hearing part of it and the opportunity to hear from you in person, which is very fortunate. What we normally do is—and hopefully this is agreeable to you both—ask for an opening statement from one or both of you, though I am not quite sure how you have decided to do that, and then we will move over to questions from Committee members, which we will then allocate across the three groups—the Opposition, crossbench and Government—to take us through to approximately 2.10 p.m. or thereabouts. Is that procedure agreeable to you both?

Associate Professor MALOUF: Yes, Chair.

The CHAIR: Thank you very much. That is wonderful. Associate Professor, could I invite you to take the lead? Were you going to make the opening statement on behalf of both of you or are you going to share it?

Associate Professor MALOUF: Yes, correct. That is correct, Chair.

The CHAIR: Thank you.

Associate Professor MALOUF: Thanks, Committee. I firstly would like to acknowledge the traditional custodians on whose land we meet on today and pay respect to Elders past, present and emerging, who cared for and continue to care for country. I also acknowledge non-Aboriginal people who are present here today. We thank the Committee for allowing us to speak with you today. The Aboriginal Health and Medical Research Council [AH&MRC] of New South Wales is the peak organisation representing 47 Aboriginal Community Controlled Health Services in New South Wales. Our primary focus is advocating for health equity whilst supporting our members in delivering high-quality, comprehensive primary health care for Aboriginal individuals, families and communities. We are pleased to have provided a submission to the Committee—and we are happy to discuss it today—which talks about some of the critical challenges faced by Aboriginal people accessing health and hospital services in rural, regional and remote New South Wales, but also the work our Aboriginal Community Controlled Health Services do in supporting culturally appropriate access to support physical and mental health.

In essence, in our submission we call for an integrated and culturally appropriate healthcare service or system for over 165,000 Aboriginal people living in regional, rural and remote New South Wales. The system must be supported by formalised and genuine partnerships between local health districts and Aboriginal Community Controlled Health Services. We know that this fragmented partnership impacts the quality care given to Aboriginal people and contributes to Aboriginal people presenting at hospital services or health services at the later end of disease progression.

Sadly, Aboriginal communities in rural and remote settings are losing family members to suicide, and many Aboriginal people in New South Wales often do not feel culturally safe when accessing health services. In rural, remote and regional settings, mental health services have little knowledge on or understanding of Aboriginal culture or history, and therefore Aboriginal people are often reluctant to seek help for mental health services. We know that better care given in the community will optimise better health outcomes needed for Aboriginal people, and we know that our 47 Aboriginal Community Controlled Health Services do recommend that the New South Wales health system needs large-scale reform to improve Aboriginal people's health and wellbeing in New South Wales in general, but more particularly in regional, rural and remote areas. Thank you, Chair.

The CHAIR: Thank you very much, Associate Professor. That is a very precise and clear opening statement, which I think sets us up very nicely for questioning from Committee members. You are okay that we proceed now with the questioning?

Associate Professor MALOUF: Yes.

The CHAIR: Thank you very much. So we will get things underway. Can I invite the Hon. Walt Secord to commence the questioning.

The Hon. WALT SECORD: Thank you, Mr Chair. My first question will actually be to both participants. In your submission you talk about Aboriginal people having a higher level of disengagement from the hospital health system. What do you mean by this? How do we, in fact, overcome this?

Associate Professor MALOUF: Sure. What we mean by this high level of disengagement with the health system is that we know that historical factors impact on Aboriginal people accessing western or traditional healthcare services. We know that, particularly in rural and remote communities, Aboriginal people have a fear factor of going into the health system because they have seen many Aboriginal loved ones and community members going through to hospital and then ending through passing away. So there is this level of fear factor, when they enter the hospital system, that they may come out deceased at the end. So there is this reluctance of going into tertiary hospitals. I guess what we were wanting to see and wanting to talk about is improving cultural-based care. That is about how do we make hospital systems more culturally appropriate and friendly for Aboriginal people to enter into the system but also afterwards. I think we appreciate that Aboriginal Community Controlled Health Services play a vital part in providing that cultural support that is needed.

The Hon. WALT SECORD: Ms Cashman, would you like to add to that?

Ms CASHMAN: The only thing I would probably add is really around the feedback from our member services, which also speaks to the disengagement, and is when people are presenting to the Aboriginal Community Controlled Health Organisations with a preference to try to receive care from the ACCHOs that they will need to receive in the hospitals. We know that that does happen. They are asking to be treated by the ACCHOs primarily, because that is where they feel safe. That is probably all from me.

The Hon. WALT SECORD: I do not know if you were watching evidence earlier today. We received evidence involving cancer treatment in rural and regional areas, and Can Assist and Cancer Council NSW said that, in fact, if you lived in Sydney, you would receive world-class treatment for cancer treatment; however, if you lived in a rural or regional area, many patients would be skipping treatment because they could only access privatised services and, due to remoteness, are unable to, in fact, financially access those services. So it must be exponentially more difficult for First Nation people in New South Wales to access cancer treatment. Do you have a view or an observation on that?

Associate Professor MALOUF: We are working closely with the Cancer Institute around understanding the nuances around the prevalence of cancer, particularly in rural and remote communities. We certainly are seeing there is a high prevalence of Aboriginal people diagnosed with cancer in those settings. Yes, we are hearing from our member services that the only course of treatment is in metropolitan New South Wales. So we want to obviously understand, within the health system, what is the capacity building, what resourcing is going to be added for regional or remote communities. We know that, if you add those tertiary services in regional or remote communities, you are optimising better health outcomes, particularly for Aboriginal people, because they are being treated on country; they are not being removed or dislocated into metropolitan Sydney for treatment.

The Hon. WALT SECORD: Ms Cashman, do you have anything to add to that?

Ms CASHMAN: I think Peter Malouf summed it up nicely. But probably just to say we are seeing some of our member services applying for grants to be able to facilitate that travel into Sydney to improve the timeliness of diagnostic services, improve the access to cancer care services. So there really is a need to build that capacity in the regions, as Peter said, definitely.

The Hon. WALT SECORD: You both are probably aware, by listening to me, that I have an accent. I was born in Canada. I know that First Nations people in Canada have a reluctance to go to hospitals because, unfortunately, in First Nations communities you only go to hospital when you are really, really sick. If you are really, really sick when you access health services, then you are going to have bad outcomes, which means deaths in hospitals. How can we make recommendations so that services in rural and regional areas will be more culturally sensitive? There is a proposal from the Australian Medical Association where they wanted to put up Indigenous paintings in emergency departments. I think you want to go beyond that. What are some tangible recommendations that we could do to make services more culturally sensitive?

Associate Professor MALOUF: Yes. I guess what we want is to formalise genuine partnerships with our Aboriginal Community Controlled Health Services in those rural and remote and regional communities because we have services that are in those settings that can offer the cultural support that is required for Aboriginal people but also can support and navigate Aboriginal patients through to the hospital system. What we are seeing at the moment is that there is this disconnect of patient journey through—when an Aboriginal patient rocks up to a hospital setting, with not giving information to the ACCHOs, they get caught unaware that there are Aboriginal patients being presented at the hospital and then discharged as well, transitioning out. So the Aboriginal Community Controlled Health Service is not a part of the discharge planning process. So what we want to see in this formalised partnership is this better working relationship with the ACCHOs in those communities so we can better streamline the patient journey so it is not as fragmented at the moment.

The Hon. WALT SECORD: We hear this phrase all the time. I was shadow Health for five years and on this Committee for the greater part of a year in health committees. We always talk about integrated care. Can you turn that into layman's language. What is integrated care that you are calling for?

Associate Professor MALOUF: Yes. When we talk about integrated care, we want both basic primary health care as well as hospital all working together, so when a patient is diagnosed and needs further treatment in the hospital setting, the care of that patient is supported by both primary care as well as tertiary care. That is that integrated component. At the moment what we see is that patients tend to fall through the gap when there is not a seamless health pathway for an individual. The reason why there is a gap is that there is no standard practice around sharing information of the patient's journey. So what we want to see is that our Aboriginal Community Controlled Health Services are the point of care for our patients but at the same time are receiving timely information of their care when they are presented into hospital but also on discharge so that again it supports that patient journey and that seamless approach for an integrated model.

The Hon. WALT SECORD: Do you find that in remote areas of New South Wales medical practitioners are being forced to resort to telemedicine? With telemedicine, are there implications and difficulties for First Nations patients?

Associate Professor MALOUF: Take the COVID situation. Certainly, telehealth has amplified the use of that particular technology. But what, I guess, Aboriginal patients require is that face-to-face interaction. The telehealth has created a barrier for mob in terms of their care management and compliance. Our Aboriginal Community Controlled Health Services do utilise telehealth, but they also have the second component, that face-to-face interaction. So if a patient is home sick, they can utilise the telehealth function—but then our services also provide the welfare check. They actually go to the home to check on the individual and how they are travelling. Telehealth and face to face need to be working hand in hand, particularly in Aboriginal health.

The Hon. WALT SECORD: I am mindful of time. I will ask one more question. We have challenges involving palliative care in rural and regional areas. But it must be extraordinarily difficult to provide culturally sensitive palliative care in Indigenous communities to First Nation peoples. What are the challenges? What can be done in that area?

Associate Professor MALOUF: We know that palliative care services, particularly in regional and remote communities, are very scarce and limited. If they are needing to go to Sydney for further treatment—giving Aboriginal people the option to go and die on country is important. It is about acknowledging cultural protocols and practices in terms of their end-of-life journey and having the system to support those cultural practices. The system needs to understand and appreciate that the patient has a right to decide on where they would like to end their end of life. The majority of our Aboriginal communities want to be back home on country.

The Hon. WALT SECORD: The challenge of COVID must be magnifying the difficulties of treatment for Indigenous people in western New South Wales particularly. How is that working itself out, involving health services?

Associate Professor MALOUF: I guess we are fortunate enough to have a number of Aboriginal Community Controlled Health Services in western New South Wales that are working together on providing better health outcomes for their Aboriginal communities. They share resources. They share staff to support the current situation that western New South Wales find themselves in. But what we want to see is better support from NSW Health, particularly in western New South Wales, to support that collective effort and also provide further resourcing for our Aboriginal Community Controlled Health Services in western New South Wales.

The CHAIR: Thank you very much, the Hon. Walt Secord. We now move over to crossbench members. Deputy Chair, the Hon. Emma Hurst.

The Hon. EMMA HURST: Thank you, Chair. Thank you both for coming here today. I am just going to ask a couple of questions in regards to your submission. The submission actually says:

> … the landscape of formal partnerships between Local Health Districts (LHDs) and ACCHOs across NSW is highly inconsistent.

Can you, just for the benefit of the Committee, explain this further and whether any partnerships have been formalised so far?

Associate Professor MALOUF: Sure. I might get Ms Cashman to respond to that.

Ms CASHMAN: Sure. What we talked about in terms of the inconsistency of partnerships is around—in some areas we see very strong partnerships between the LHDs and the ACCHOs. Those partnerships are often linked to resourcing, and they involve clear outlines around the service delivery for the ACCHOs and how that works with the hospitals. In other regions, we do not see any partnerships or we see very surface-level partnerships that relate to just documentation. What we see in particular in some areas is where the LHD might have a partnership with a regional body and the regional body may represent some of the ACCHOs in that region—but there needs to be an onus on the LHD to ensure that they have some form of partnership with every ACCHO because we do not want to see any ACCHOs left behind in that system of care.

The Hon. EMMA HURST: You also note that there is lack of representation of Aboriginal people in the senior levels of the LHDs. Do you think that actually having targeted positions or roles to increase representation would be helpful for some of the issues that we have been talking about?

Ms CASHMAN: Yes, I do. I think that is very important, moving forward. Aboriginal people need to be very much in control of decisions that are made regarding the health of Aboriginal people. Peter Malouf and I are lucky enough to work for a fantastic CEO and Aboriginal board, who direct the work of the AH&MRC. I think that sentiment being included in the governance of the hospital system, yes, is important. But I would defer to Peter if he wanted to add anything to that.

Associate Professor MALOUF: No.

The Hon. EMMA HURST: In places where there is an absence of any kind of formal partnership—I imagine that makes it very difficult to support patients in hospital and other healthcare settings. Can you give us any examples of some of the on-the-ground difficulties that you may have heard of arising from the lack of formal partnerships?

Ms CASHMAN: I think a particular difficulty that I have come across this year from our member services has been around the delivery of mental health services where there are not good partnerships. Obviously, our member services are able to provide a level of mental health services to the community. But at times people will require acute care from a hospital setting where there is no partnership and there is lack of information-sharing processes. That has been reported to us as being particularly difficult to ensure that in a time of crisis people are completely supported the whole way through their journey because, obviously, health professional are catching up on what is happening. People then have a delay in the care that they are provided. [Disorder].

Associate Professor MALOUF: Yes. What we see at the moment with the COVID crisis in western New South Wales is that we do not—not having a formalised partnership with our Aboriginal Community Controlled Health Services with the LHD has seen this kind of disconnect of response around managing case numbers and supporting families' and individuals' welfare. We see the State Health Emergency Operations Centre committee, particularly in western New South Wales, do not have Aboriginal community controlled—not even the CEO at the committee table to talk about the response in western New South Wales. I think this demonstrates the need and the downfalls in this partnership, what are trying to talk about here.

The Hon. EMMA HURST: You mentioned also that, by not having any kind of formal partnership, there could be also duplication of services as well. Can you give us a bit more information about that? Is that something that you are currently seeing happening on the ground?

Associate Professor MALOUF: Yes, there is definitely duplication of services from our LHD as well as our Aboriginal Community Controlled Health Services. Tertiary hospitals are really focusing on the tertiary needs of individuals, and community-care-type arrangements or community health should really be driven by primary care providers, which is our Aboriginal Community Controlled Health Services. So we want to be able to work with the LHDs or the local health districts to reorientate those efforts back into community control because again that would demonstrate service integration. We would see that our services are working in tandem with the tertiary health needs of individuals from a hospital perspective.

The Hon. EMMA HURST: Thank you. I will throw to Cate Faehrmann.

Ms CATE FAEHRMANN: Thank you both for appearing today and for the good work that you do across the State. I do think it is extraordinary that the Government has not committed really to building these partnerships with the ACCHOs and the LHDs. I see in your submission you refer to the New South Wales State Health Plan *Towards 2021* and that that is a commitment in that health plan, which I think was written or released in 2014. Is it a situation that the Government just isn't taking this seriously? Do you feel respected and listened to and able to influence NSW Health in this area?

Associate Professor MALOUF: I think we have had conversations in the past around developing a statewide Aboriginal health plan and partnerships. But it becomes a talking-fest. We just go around in circles. Again, all local health districts all have to comply, as part of their national accreditation as a hospital, to the National Safety and Quality Health Service Standards. There are six action items that are specific to Aboriginal and Torres Strait Islander health care. Action 2.15 talks about working in partnership. It clearly outlines what the hospital needs to do in terms of meeting their accreditation standards and working in partnerships in Aboriginal and Torres Strait Islander health. In that point it talks about having formalised partnerships with Aboriginal Community Controlled Health Services as well as Aboriginal community-controlled organisations, those other social and non-health-related services as well, in terms of their accreditation. Instead of having a New South Wales plan, we want to see localised plans with our Aboriginal Community Controlled Health Services.

Ms CATE FAEHRMANN: We heard this morning that the LHDs have key performance indicators, which are largely around budgetary meeting, financial KPIs. They are operating within a system where they are not really trying to do things new and expand; they are just trying to keep within budget because that is their KPIs. Do you think that—obviously, there are formalised partnerships—KPIs around engagement with ACCHOs, KPIs that reflect what is in the State plan as well need to be put in place?

Associate Professor MALOUF: Definitely there needs to be KPIs in the State plan that reflects the formalised partnership with our Aboriginal Community Controlled Health Services. But I also think that, if LHDs are concerned about budgetary constraints, then they need to really consider what is their real purpose. In terms of community-based care, they can certainly be provided by primary care providers such as Aboriginal Community Controlled Health Services. Hospitals just really focus on those tertiary and specialist care that they are funded to do. What we know in terms of the activity-based funding model from the Commonwealth through to the States is that for an Aboriginal patient who enters a tertiary hospital—we know that there is a 3 per cent loading that is applied to an Aboriginal patient. They actually get a 3 per cent cap on an Aboriginal patient that comes in because they know that Aboriginal patients have complex needs and social supports that need to be supported. We know that that 3 per cent loading could really be supporting our community-controlled health services in providing what they already provide, which is that comprehensive support and holistic care that can be provided to that individual once entering into the hospital system.

Ms CATE FAEHRMANN: Thank you. I just wanted to ask now a slightly different angle in relation to people becoming Aboriginal health practitioners and making sure that there are enough First Nations people going to study medicine and nursing and allied health. Can you make any recommendations in that regard? Are there problems in that area?

Associate Professor MALOUF: Particularly for Aboriginal and Torres Strait Islander health practitioners there is not enough funding to support RTOs, or registered training organisations, to support a young person to be supported to do that qualification as well as to be coming out as a practitioner. So there certainly needs some funding and resources in that space. I know that universities are changing the way that they attract and retain Aboriginal students. We know that, for example, particularly in Dubbo—there is the Murray-Darling Basin funding that has been allocated to develop a medical program in Dubbo. That is allocated for Aboriginal, as well as someone from a rural background, to actually do a four-year medical degree in Dubbo. There are those innovative programs that are happening, but we need to do it more broadly to attract the other disciplines, such as nursing and allied health, in that space. By ramping up the health workforce, you create a more culturally appropriate and safe environment for mob to enter into.

Ms CATE FAEHRMANN: Just in that regard do you think there is too much demand from Aboriginal and Torres Strait Islander people who are wanting to study or are studying in this area? Is there too much demand for the supported places available? Is that your experience?

Associate Professor MALOUF: In terms of support demand, my experience is that there is not enough. Putting on my adjunct position with the University of Sydney—we are certainly advocating through the Commonwealth to make sure that there are more Commonwealth-supported places for Aboriginal people to actually enter into those medical degrees or health degrees. There certainly needs to be more emphasis and targeted supported places. We are advocating at the moment for that.

Ms CATE FAEHRMANN: Thank you. I just now wanted to turn to the issue of overall health and wellbeing and preventative health, the services that the ACCHOs provide. Is there more funding needed for programs in this area generally? Are there any recommendations around that?

Associate Professor MALOUF: In terms of the services that our Aboriginal Community Controlled Health Services provide, they provide a plethora of programs and services. When an Aboriginal person enters an Aboriginal Community Controlled Health Service, they can come in for their health check but also come for their social and welfare needs, as well as other social needs as well, whether it is employment or training. It is basically a one-stop shop that actually looks at a holistic kind of approach to Aboriginal care. But, again, our ACCHOs do not get funded enough to provide those other social support needs. The only funding that they receive is purely on their primary healthcare component. But we know that, if you address the social needs of individuals, they would be more productive in society and their health outcomes would decrease if you look after the social needs.

What our services provide is that comprehensive view around health care. But, again, they do not get funded enough for those social supports and programs.

Ms CATE FAEHRMANN: This is my last question, Chair. Just remind us of the funding breakdown. Is it all standard across the State for ACCHOs? A certain percentage, obviously, comes from the Feds. Could you just quickly remind us of what that is?

Associate Professor MALOUF: Sure. Probably 70 per cent of their core funding comes from the Commonwealth. Then there is a small amount of money—probably about 10 per cent, closer to 15, maybe, comes from NSW Health. The rest comes from self-generated money and opportunities that they endeavour into.

The CHAIR: Thank you very much. We will move the questioning now to the Hon. Wes Fang.

The Hon. WES FANG: Thank you so much for appearing today. I really do appreciate you taking the time to provide us some insights to the views of Indigenous people with rural and regional health because I think it is vitally important that we get this right. To that end I noted in your introductory statement you talked about culturally appropriate spaces and treatments. Can you just provide a bit more elucidation on that and what is it that you think that we might be able to do better to engage and work with the Indigenous population to make sure that we do that. But also can you provide perhaps some insight as to how it is that we are currently engaging in that space. I know that we have got a checklist that has been produced. In your real-life experience on a day-to-day basis, how are those tools working? Do you think that there is need to make changes to them? Or, if they are working well, what about them is working well?

Associate Professor MALOUF: When we talk about cultural safe care or culturally appropriate care, we are talking about systems and services that acknowledge the history of Aboriginal people as well as their culture. That could be through acknowledging the lands which the building is built upon. It could be staff entering into understanding cultural histories through cultural awareness training or cultural immersion programs. It could be allocating spaces for Aboriginal people, such as a healing garden or spaces where they are connecting to country. That is when we talk about culturally appropriate care. On top of that, it is also about the health system acknowledging cultural-based practices. For mob, we still practise our traditional healing practices. So that needs to be incorporated into whatever care that is given to an Aboriginal patient in the health system. It is acknowledging that they have a right to cultural-based care.

I guess what is working well is that we do have some Aboriginal Community Controlled Health Services that work closely with Aboriginal staff members within the hospital to acknowledge that cultural-based care. That is the kind of lower-level kind of things that we do not necessarily see but we hear about. We know that Aboriginal people have a strong kinship system. Whether you work in Aboriginal Community Controlled Health Services or you work in the hospital, they all have the same common ground, which is about the best care of their mob. So they will work tirelessly to ensure that they are getting the best cultural care. I think it is important to acknowledge that. I am just going through them. There was multiple questions in that question.

The Hon. WES FANG: I tend to do that. I have lots of thoughts that are running around. I like to just get them all out there and then see what transpires. Then I like to elucidate on some of those positions. If you need something repeated, ask by all means. We have got the Aboriginal Cultural Engagement Self-Assessment Tool that NSW Health has put out there. I am just curious as to your experience, perhaps having worked with it—I do not know if you have or not—and if you could provide some feedback as to how it works and how those tools that we have, as NSW Health or the New South Wales Government, are helping the services and the groups that are stakeholders to engage and connect.

Associate Professor MALOUF: I think it is important to note that, yes, you can have tools to tick off about whether or not a health service is being culturally appropriate, but at the end of the day it is about people and services working closely with community on the ground. When we have people that develop checklists, it really becomes a tokenistic kind of gesture to say that, yes, we have ticked all these boxes to say, yes, we are culturally safe. But are you really? The only way to measure cultural safety is by actually yarning with Elders and community members about their experience of the healthcare system and also seeking their advice and the guidance around what strategies should be applied within the healthcare system.

We often dismiss Elders and community members when we come to develop strategic plans or health plans. We should be working with and working together with Elders and communities to design what is the health system they want to see? What are the things that they need to support them whilst they are navigating the complexity of the healthcare system? I think it is important that we now, when we develop State plans, take an active listening role to community and actually hear what they want.

The Hon. WES FANG: It just struck me, actually, as you were answering that, that you were talking about how it could be tokenistic to have these tools and that what we really need to do is engage and yarn with each other to find out how it is working. It dawned on me that that is exactly what it is that you and I are doing now. The tool is there, but what I am doing is asking about that lived experience and how your engagement with the tools that NSW Health has actually increased that feedback loop and ability to interact or whether it could work better. That is awesome, what it is that we are doing now. Has that been happening at all, not from me but from other members of the Government or people within NSW Health? Are they getting that feedback loop about the tools that are being put out there in order to try and increase that cultural awareness?

Associate Professor MALOUF: We have certainly heard from on the ground that the tool has not been useful in terms of building the relationship with our Aboriginal Community Controlled Health Services as well as community. I guess that is the fault of people that developed the tool. There has not been a co-design process with Aboriginal and Torres Strait Islander people. That needs to occur. The other thing here is that we know that NSW Health have developed the Respecting the Difference program [inaudible] cultural kind of awareness. But we know that in New South Wales there are many traditional language groups and you cannot just develop a training material that is standardised.

I think, if we are going to develop genuine partnership or have a genuine dialogue with community, that we develop localised cultural awareness programs that the local health districts can access. We certainly are seeing that with Waminda. Waminda has the cultural immersion program, which their local health district's staff participate in. There are things happening across the State. But we want to see it more, not having the Respecting the Difference as a mandatory requirement but more cultural awareness and mandatory requirements that staff utilise local content instead of the just generic program.

The Hon. WES FANG: Do you think it is fair to say that in the past, say, two decades or three decades we have seen an improvement and that the health services that the New South Wales Government provides have been more focused on being culturally aware and culturally appropriate to Indigenous people? How do you think we have been progressing in that time? Other than making it more localised, what else do you see as important for us to focus on into the future?

Associate Professor MALOUF: It gets back to the fact that there are some parts of NSW Health that have started the dialogue with Aboriginal communities to develop a shared kind of approach and developing cultural safe practices or strategies. But I think what we need to do is actually have a genuine conversation about how do we develop not just an Aboriginal health plan but an Aboriginal health plan that steers and redirects the health system to be culturally safe and responsive. That is about how we develop stronger and formalised partnerships with our Aboriginal Community Controlled Health Services. What we want to also see is a genuine dialogue with our Aboriginal Community Controlled Health Services CEOs in those communities so that they can be a part of the hospital's health service planning as well as other activities that the hospital may be venturing into. So I guess it gets back to that point of just re-establishing those formalised partnerships. But I might pass it on to Ms Cashman if she has any comments.

Ms CASHMAN: I guess the only comment that I would make is when you were asking the question of has NSW Health improved in its delivery of culturally safe care—we really need to ask the Aboriginal communities who are accessing that care what that looks like. That speaks to, again, looking at the hospital having a role in or an accountability in their engagement with communities, with ACCHOs, with CEOs, all of those things.

The Hon. WES FANG: Thank you very much for providing that feedback because it is very important for us. It is important across the whole aspect of the different cultures that we have in New South Wales. I think, if we can improve aspects here, then we can improve it across the whole spectrum. That is something that is important to making sure that we have timely and correct health care provided to people all across this State. Thank you very much for the feedback and your input.

Associate Professor MALOUF: Thank you very much.

The CHAIR: Thank you, the Hon. Wes Fang, for a very good number of pointed questions there. The answers have been very fruitful. Can I take this opportunity to thank you both once again for making yourself available. It may not have seemed to be a long period of time on the clock, but we covered a fair bit of terrain. I think, when we sit down and look at the *Hansard* in the next day or so, we will see there is a lot of rich information in there which will help inform our considerations around the drafting of the report and its recommendations, which will, obviously, be also taking into account your contribution through your submission. So once again, on behalf of the Committee, can I thank you both and thank also the Aboriginal Health and Medical Research Council of NSW for all the most important work it does for and on behalf of our Indigenous brothers and sisters across the State. Thank you very much.

(The witnesses withdrew.)

(Short adjournment)

ALEX STEPHENS, Director of Research, Northern NSW Local Health District, and Chair, NSW Rural Health Research Alliance, affirmed and examined

ANDREW SEARLES, Associate Director – Health Research Economics, Hunter Medical Research Institute, affirmed and examined

The CHAIR: A warm welcome to our next two witnesses this afternoon. Thank you very much. Can I commence by acknowledging the submissions that have been made. Dr Stephens, you would probably be aware that your submission has been provided, received by the Committee secretariat, processed and stands as submission No. 182 to the inquiry. Professor Searles, likewise your submission has been received, processed and stands as submission No. 467 to the inquiry. What that means is that both of those therefore stand as evidence before the inquiry. The Committee is very grateful for you both this afternoon to provide us with the opportunity to receive some oral evidence from you, which will arise, no doubt, from Committee members wanting some matters elucidated from your respective submissions. Also questions will emerge from the dialogue that we have. In making your respective opening statements, there is no need to refer in detail to your submissions because you can take them as read by the Committee. We will hear a few minutes of an opening statement from both of you and that will set up nicely the questioning, which will take us through to the end. Gentlemen, are you okay with that format for this afternoon?

Dr STEPHENS: Yes, thank you.

Professor SEARLES: Thank you.

The CHAIR: We will start with Dr Stephens with your opening statement.

Dr STEPHENS: Thank you very much for the opportunity to appear before the Committee. So it is noted, I am Dr Alex Stephens. My substantive role is the director of research at Northern NSW Local Health District but today I appear before you as the chair of the NSW Rural Health Research Alliance. Briefly a bit about the alliance: The alliance was established in 2018 to grow research in rural, regional and remote New South Wales and support the generation and use of robust research evidence with the view to improve the delivery of health services and create healthy communities.

The alliance is strongly supported by the rural LHD chief executives and the steering committee comprises of representatives from each partner LHD—that is, typically the research lead. The alliance's submission to the inquiry focused on the existing evidence on markedly poorer health in rural, regional and remote areas. Higher rates of emergency department use and hospitalisations, poorer health risk factors, higher mortality rates and lower life expectancy highlight this. The submission also cited research investigating the role of social determinants in explaining some of this evidence.

The submission, in terms of socio-economic status, looked at the role it played in explaining some of the inequalities, particularly life expectancy. It highlighted some research that showed that once socio-economic status was adjusted for, life expectancy differences between metropolitan and rural New South Wales were minimal. This research combined with other existing studies suggests that a person's position in society, their living conditions and opportunities for education and employment have a direct bearing on their exposure to risk factors for disease and poor health that ultimately impacts their life expectancy. This describes the contemporary view of health through the lens of social determinants.

All this serves to highlight the crucial role research should have in addressing the current health inequalities in rural, regional and remote areas. Research through a comprehensive health informatics and data analytics platform can systematically map burden of disease by key socio-demographic factors, such as socio-economic status and remoteness, to better understand areas of greatest need and establish priorities. Through this strategy, dedicated investment into the application of current evidence-based programs to systematically address the underlying causes of inequalities in these priority areas can be planned and delivered.

In line with the research paradigm, such programs can be comprehensively evaluated through a combination of qualitative research to understand the experience and process of implementation and also quantitative research to objectively assess outcomes. Collectively, this evidence-informed approach represents a strong framework upon which meaningful change can be introduced, implemented and assessed in rural, regional and remote New South Wales. Thank you, Chair.

The CHAIR: Thank you. That has set things up very nicely, I believe, for some questioning in a moment. Professor Searles, do you have an opening statement you would like to give?

Professor SEARLES: Honourable members, thank you for the opportunity to participate in this inquiry. I am the strategic lead of the Hunter Medical Research Institute [HMRI] health economics team, as I have already stated. We are a unique team in regional New South Wales and also in Australia. Our remit is to work with health services and health researchers to understand the cost and the consequence of health technologies that are used in our system. This work is a means to determine the value of health care that is provided to patients.

When I talk about health technologies, I am including devices and medicines—at that level they tend to be very well evaluated, particularly at the national level—but I am also referring to models of care, diagnostic tests, right through to health policies and public health initiatives. My focus is the health care deployed at the local level in health districts, hospitals and primary care in urban, regional, rural and remote New South Wales. At this level, evaluation has typically not been optimal. Today's evidence that I am presenting draws on a report that we conducted—a national report—titled *The Local Level Evaluation of Healthcare in Australia*. I believe this has already been provided to the Committee.

To be succinct, some key findings that I think would be relevant to this Committee are: Firstly, despite Australia having excellent national and State agencies to evaluate health care provided to patients, we have a gap in evaluating health care delivered at the local level. Secondly, local level evaluation is important to account for local context—for example, differences in demography, patient draw areas, healthcare resources, geography and disease burdens. Local context is important because the models of delivering health care that we might use in Bondi, may not work in Broken Hill. Thirdly, health services have been clear to us that they want access to evaluation skills and they want capacity building in evaluation and implementation amongst their own staff. We conducted national work to identify the evidence behind that statement.

Fourthly, evaluation provides evidence for decision-making as to whether a health technology should be introduced, retained or removed from a healthcare system. However, health services have problems accessing the required skills and some of these skills include—that are in short supply—skills and evaluation implementation and health economics. My fifth and final finding that I think is relevant to the Committee, is that there is a lack of evaluation and monitoring post-implementation. What I mean by that is that after we have introduced it, we do not always follow it up to see if that technology is delivering the benefits that we thought it was going to.

Our national report had four key recommendations. Firstly, to develop national standards for evaluation to ensure a uniform approach to evaluation of health care across local health services. Secondly, to boost education and training at professional development in evaluation and implementation within the health workforce, particularly amongst clinicians and managers. Thirdly, increase the available workforce of skilled evaluation and implementation staff at the local level who are integrated with health services. Fourth and finally, to make the funding for evaluation and implementation sustainable at the local level so that local health services can use these services in decision-making.

Our team is implementing some of the more detailed recommendations from our national report in three New South Wales local health districts and a primary health network via a medical research future fund program called the Embedded Economist. The Embedded Economist was designed based on the needs that were expressed to us by health services. It places a health economist within the local health service specifically to work on projects that have been selected or prioritised by that health service. It is currently being independently evaluated. The report that I referred to earlier provides greater detail than I have provided in this statement. I also would like to thank you for the opportunity to present to the Committee.

The CHAIR: Thank you. That, too, is a very fruitful opening statement, which I am sure is going to lead to a number of questions from Committee members. We will get our questioning underway, with approximately 12 minutes per group. We will start with the Opposition. The Hon. Walt Secord?

The Hon. WALT SECORD: Thank you, Mr Chair. Thank you, Dr Stephens and Professor Searles. Dr Stephens, just so I can get context, is your alliance—the NSW Rural Health Research Alliance—funded and administered by NSW Health?

Dr STEPHENS: We are currently an in-kind network of research representatives from all of the rural local health districts in New South Wales. There are seven of us. We were formally funded when we formed in 2018. It was modest funding and we had enough funding to support a program manager being in place. There is currently a review of research structures in New South Wales. As part of that review, the funding for the moment has been paused and we remain an in-kind network.

The Hon. WALT SECORD: But the seven local health districts are under the cloud—not under the cloud, but in relation to the local health districts.

Dr STEPHENS: We are from the local health districts. That is correct.

The Hon. WALT SECORD: So you do answer to government and you receive your funding and assistance from government. I just wanted to take you back to your opening statement where you said—I do not want to put words in your mouth, so please clarify this if that is the case—you did not see that there was a difference between rural and metropolitan health outcomes once you take aside social determinants. Is that correct?

Dr STEPHENS: That is only one view of it. The research was based on data collected quite some time ago, but it introduces the concept of social determinants as being a driver of some of the health inequalities that we see. It is basically suggesting we need to look at it from a slightly more sophisticated level than just saying that there are health inequalities. We need to understand what are the drivers and what are the causal factors which account for the inequalities. Social determinants in the context of life expectancy probably plays a large role and maybe for other population health metrics, but it is not the sole thing that contributes to health inequalities.

The Hon. WALT SECORD: But you are making the case that there was no difference between rural and metropolitan outcomes, once you take that out.

Dr STEPHENS: Just for life expectancy. Once you adjusted for it in the methods that we used, it accounts for the bulk of the inequalities. Apart from the most deprived population, living in the rural areas still had a large difference between their equivalent socio-economically ranked counterparts in metropolitan areas.

The Hon. WALT SECORD: I am trying to get to the point that your research is not making excuses for the State Government to say that the health outcomes are not different in rural and regional areas and city areas. That you are actually—

The Hon. WES FANG: Point of order: That question implies that their research is somewhat controversial. I think that the Hon. Walt Secord has the right to ask questions about it, but to make implications to these witnesses is probably a little bit beyond pale.

The Hon. WALT SECORD: Mr Chair—

The CHAIR: I think maybe a small reconfiguration of the question will deal with this. Just bounce back the question and see where we get.

The Hon. WALT SECORD: I would like to thank the Hon. Wes Fang for getting to what I was actually trying to get to. I am trying to make the point that is your research to improve health outcomes for rural and regional families or is it to make excuses that there are not adverse outcomes in rural and regional areas once you take aside social determinants? I put to you that, in fact, you are just making excuses for the disparity between rural and regional health.

Dr STEPHENS: Let me be perfectly clear that the research is in no way designed to make excuses for the health inequalities that we see in rural, regional and remote areas. What it is highlighting is that there are underlying causal mechanisms that need to be explored and understood to then develop solutions tailored to addressing the causes of the inequalities.

The Hon. WALT SECORD: I see in your submission you identify the consumption of sugary drinks in rural and regional areas as one of the reasons for poor health outcomes. Can you elaborate on that?

Dr STEPHENS: That is sort of superficial evidence to support the argument that social determinants have a role in explaining some of the inequalities that we see in metropolitan versus regional and remote areas. Right? Social determinants in itself is quite a complex concept and what it does suggest, if I can explain it very briefly, is that there are social and economic conditions that act as preceding factors that influence health behaviours, lifestyle choices, access to care, opportunities for education and employment that themselves have an association with adverse health outcomes.

The Hon. WALT SECORD: In rural and regional areas—as you said in your opening statement—there is higher visitation to emergency departments. Why is that?

Dr STEPHENS: I think you probably need to explore it on a deeper level. We do see that there are higher rates of emergency department use, but we also see that there is a lower density, for example, of primary care. I cannot definitively answer that there is a causal mechanism there, but there is a causal mechanism that you could use to undertake an activity or a research project to try and understand whether that is a driver or not.

The Hon. WALT SECORD: Preventable diseases.

Dr STEPHENS: That is just emergency department hospitalisation. You can explore—if you have a look at the fundamental principles of primary care, which is largely around the first point of call for people seeking health care, they provide a comprehensive suite of services—preventive health, mental health and chronic disease management. If you have got lower levels of that, what are the implications? You cannot prevent disease progressing if you cannot prevent disease at all. If disease develops, for example, you get higher rates of ED usage.

You get higher rates of high acuity ED usage. They are the types of things I am suggesting are worth exploring to definitively reveal, in a way, what the causal factors are, to then tailor solutions to address them in a robust and scientifically rigorous way.

The Hon. WALT SECORD: Dr Stephens, in rural and regional hospitals, what is the most common condition that families or people in rural and regional areas are being hospitalised for?

Dr STEPHENS: Look, I could not tell you but it is very similar, in a way, in terms of what people need hospitalisation or hospital care for in rural areas than metropolitan areas. Right? All the major diseases are still the same. What is the biggest difference is the population burden of disease in regional and remote areas and the rate at which it develops. You are more likely to present with illness earlier in regional and remote areas than you are potentially in highly affluent areas in metropolitan centres, and the population distribution—the burden—is likely to be greater as well. These are only my words. There is probably an approach to identify this data to source it to definitively answer your question and I do not have that answer.

The Hon. WALT SECORD: Can I take you back a step. You said that people will present to hospitals earlier in rural and regional areas. That is not the evidence that we had in other occasions. We had that people are reluctant to go to hospitals because they find that there is a lack of confidence in rural and regional facilities. You have hospitals that do not have doctors on the weekend and you have hospitals where you have to wait—as stated in earlier evidence today—four days to get a specimen or a sample or a test back.

The Hon. WES FANG: Sorry. The Hon. Walt Secord is making assertions here. I am struggling to actually identify those indications that we have had during this inquiry. I think that they are very broad generalisations, Chair, and I would ask you to direct him to a more direct question.

The CHAIR: With the greatest respect, the Hon. Walt Secord is in order with his question. Please proceed.

The Hon. WALT SECORD: Thank you, Mr Chair.

Dr STEPHENS: What I will say, if I made a reference to them seeking care earlier, I probably was not correct. What I was alluding to is that disease is more likely to develop at an earlier stage. I will substantiate that by basing it on research that I undertook exploring the consequences or the contributing factors to lower life expectancy experienced by people living in rural and regional areas. You see that they are basically dying from the same common conditions that we see in metropolitan areas—chronic diseases, cancers and so forth—but the contributions are due to illness occurring earlier in life. So the disease develops earlier than you might expect in metropolitan areas and potentially in more affluent centres.

The Hon. WALT SECORD: Professor Searles, in your health research economics, do you do modelling on productivity and the impact of preventable diseases in rural and regional areas on the economy and economic output?

Professor SEARLES: We have not done specifically that type of modelling, but we are working with one of our local health districts to increase their focus on prevention for productivity reasons. The idea being that it is more cost-effective to identify disease earlier in its cycle and address it then, rather than waiting until the disease has progressed and then, of course, people need more intensive and more expensive usually hospital care.

The Hon. WALT SECORD: Thank you, Professor Searles. You actually answered my question. What are you finding? That every dollar you put in early results in a saving or a benefit to the community down the track? What are you finding in that area?

Professor SEARLES: What we have looked at—we have not done that specific modelling but we have borrowed information that has been put out by the Productivity Commission in Australia. One of the key gaps we have in Australia is that there has been very little work done on evaluating preventative care. As a consequence of poor evaluation in that space, Australia has tended—compared to other countries overseas with similar health systems—to under invest in preventative care. You are absolutely right; it is a productivity issue. If we can identify where we can get the best value from putting our health dollars, of course that can help decision-makers determine where we should be allocating them. That is where health economics can come in, but it is a very broad area. Our focus has really been (a) identifying the existing literature—a lot of it comes from the Australian Productivity Commission—and then working with local health districts to identify how they can actually increase their focus on prevention.

The Hon. WALT SECORD: Thank you. Mr Chair, I think that is my time.

The CHAIR: Yes, it is. Thank you to the Hon. Walt Secord. We will move now to questions from the crossbench. I call the Deputy Chair, the Hon. Emma Hurst.

The Hon. EMMA HURST: Thank you. I will go to Professor Searles first. I was quite shocked to hear that there was no sort of evaluation being done, particularly on new health technologies that were being brought in. I think in your submission you also highlighted that even when new technologies enter the health system that there is often no assessment of patient benefit. What does this mean in a practical sense? Does it mean that we have got hospitals with technologies that they are not using and that are not useful in those particular locations? What does that mean broadly?

Professor SEARLES: Just for a correction, we are not saying that there is no evaluation; we are saying that the evaluation is not optimal and, because it is not optimal, we have many health technologies (a) that have actually come into the system in past times where they have never been evaluated. They have come into the system and they have remained in the system and just become part of the way that we do things. They may be effective; they may not be. Because it is not being evaluated, we cannot be too sure. More and more, particularly with agencies like the Agency for Clinical Innovation within NSW Health, there is now more of an ethos in terms of ensuring that new models of care and technologies are evaluated so we do know what those patient outcomes and patient impacts are going to be. However, there is still a shortfall. We work with our local health districts to try and identify ways that we can build into the system routinely collected data so that we can actually see if somebody has been exposed or has utilised a particular model of care what their downstream impacts are.

Often what happens is we do the initial evaluation for a model of care and it might get the tick because initially it is deemed to be cost effective under trial conditions, but real world conditions are often very different. It might be that in the trial we have got very strict criteria for how a particular technology is being rolled out—whether that be how patients are taking medications or it might be for diabetes control or it might be how we actually bring patients into the system. Under a trial, that can be really rigorously controlled. When we move to the real world, things do not always happen like that. It is the real world outcomes and impacts that we are particularly interested in. We are particularly focused in trying to help health services routinely build in those kind of metrics so that they can actually say, "We are not getting the benefits from this model of care that we thought we were going to."

The Hon. EMMA HURST: The best way to optimise those evaluations is going back to what you said in your opening statement. You made a list of evaluating and training for evaluation and increasing funding for evaluation. That list is how we get to optimise on that sort of ground level.

Professor SEARLES: Yes. That was sort of the overall picture. Our report is more detailed in how to get that. There is quite a bit of detail that goes into this. One of the points I would like to make is that in our national work—so that was not just New South Wales; it was across Australia—in fact, the health workforce are actually very interested in evaluation. These are clinicians who are at the coalface, who actually want to know how to evaluate what they are doing, but they do not want that to be the prime component of their job. They need some help on how to do this. In a way, it is actually building in—in my view—evaluation as business as usual.

The Hon. EMMA HURST: Dr Stephens, in regards to your research, you have talked about these social determinants. I was wondering if when you were looking into these are social determinants you had assessed at any point a correlation between certain social determinants and rural or regional areas or whether that kind of splits depending on the area. If you could please explain that out further in regards to correlations that came up in that data set.

Dr STEPHENS: The approach to the work was about really defining how socio-economic status worked separately to remoteness. It is a term we use, for example, when you undertake a statistical analysis that you adjust for it. To describe it is to create strata groups that represent combinations of remoteness and broadly socio-economic groups. Once you do that stratification you can assess, in a way, the independent effects of socio- economic status versus remoteness. Part of the reason for doing that work in my research is that is commonly not an approach that is taken. In a way, it probably reveals one way to try and separate socio-economic status from remoteness effects because they are probably two slightly different things. When you look at geography, you are probably assessing access to care and whether you have healthcare services in the area. When you are looking at socio-economic status, you are looking more at things like social determinants, which is your material wealth, your income, your housing, your education and your employment. Right? So the whole reason behind the analysis was to separate them. They are correlated because it just happens that there is an overproportion of disadvantaged Australians living in regional and remote areas.

The Hon. EMMA HURST: With the dataset that you came out with, was it largely correlational based on large groups of people being assessed or were there causations coming through as well?

Dr STEPHENS: These are population-based datasets—for example, life expectancy work is based on the register of deaths, births and marriages. If you look at some of the other sort of administrative data collections, you can look at hospitalisations, emergency department presentations and so forth, you can do the same type of work. It is epidemiological in nature. We do not have the luxury of being able to identify the causal factors, but we can identify the associations.

The Hon. EMMA HURST: Thank you.

The CHAIR: Thank you, Deputy Chair. Cate Faehrmann?

Ms CATE FAEHRMANN: I just want to go to some allegations that we have heard throughout this inquiry about there being a culture of silence within NSW Health, particularly in relation to complaints that medical staff make about the system and ways to improve the system. Often they say that it is actively discouraged and also usually ignored. I just wanted to get a sense whether that is the situation within your research organisations and whether your researchers are also—if they are uncovering or finding situations that need to be improved, how is this being accepted by the LHDs and by NSW Health? Is it accepted with open arms? If you could be as frank as you can, that would be wonderful. I will go to you first, Professor Searles.

Professor SEARLES: Thank you. Our experience has been because we work on the ground with clinicians—and just to let you know my background, I come from the private sector. I have come into this role with an understanding that if you want things to change, you often need to put a business case forward and you need to have a good case as to why we should stop going in this direction and perhaps pivot. My experience in working with clinicians is quite often the business cases were not necessarily what decision-makers were looking for. They did not always clearly identify what were the costs and the consequences from a particular course of action. That is nobody's fault. That is not part of the training process that a lot of clinicians go through. In fact, it is not part of the training process a lot of health managers have gone through.

Part of what we are trying to do is to get the clinical information to understand the costs of a particular technology and to bring them together into a short and concise business case that can go to decision-makers so that they can see that if we make this decision and we are making a pivot to either remove or to bring something new in, this is what the likely outcomes would be. We also advise our colleagues in the health services: do not just rely on that first pass, also identify how you will actually follow that up. If we are saying we are going to remove a technology because the evidence for it is not clear, how do we know it does not creep back into the system? What will we do to make sure that we are monitoring that so that it does not creep back into the system? If we are introducing something new, what is a particular metric that we might use so that in two years' time we can see is it actually delivering the benefits that we thought it was going to?

None of this is rocket science, but it is bringing a little bit of that—what I would sort of say—business way of approaching a problem and bringing it into the health workforce as well. That has been our experience. My personal experience has been that if we can actually help clinicians put that business case together, so that it is based on evidence and it also shows cost, they have got a very good chance of convincing decision-makers for the way that they would like it to go.

Ms CATE FAEHRMANN: Dr Stephens, do you have anything to add to that? I have got a follow-up question for Professor Searles, but you go.

Dr STEPHENS: I do not have too much to add apart from being slightly complementary, I guess, to what Professor Andrew Searles is saying. I have a spin on it from the rural and regional perspective. I think what Andrew is talking about is developing a robust and rigorous framework to guide change, if we are going to go down the path of doing it. We have just got a general lack of capability and capacity to do that in regional and rural areas. Some of the work Andrew is doing with the HMRI embedded in local health districts is a fantastic example of what you can do in that space. The only other thing I will say is that, we are slowly becoming more innovative in regional and rural areas. Each of us have research directorates. There is also broad encouragement across a number of structures. NSW Ministry of Health has different pillars to engage in continuous quality improvement. That does occur, but probably not in the rigorous way that we would want. Just like Andrew was talking about, we just do not have all the puzzle pieces there to do it rigorously.

Ms CATE FAEHRMANN: I assume there would be quite a few GPs or clinicians, for example, who do not go through your organisations or do not seek assistance with the business plans that you were saying, Professor. Their chances are a lot more improved if they go through you, but many would not know to do that. Many would not approach you.

Professor SEARLES: We have also been working with our local primary health network [PHN], to within their staff—I think one of the things that I would like to say is that I do not believe the skills that I am talking about are only found within health economists. I believe that it is actually a very generic skill that we can actually share across the health workforce. You might find some pockets of expertise in not only doing the evaluation but communicating them. Communicating them is really important. When you get the results, you cannot give somebody a 500-page report and expect them to make a decision on it. It just will not happen. You want a business case, three pages absolute maximum, that identifies the core findings with appendices if you do need that. Our work—we are only a very small team, so we do work with the PHN. Most of our work is with the clinical workforce within the LHDs. As it is now, we are run off our feet. We are beyond what our team can satisfy.

Ms CATE FAEHRMANN: That was kind of leading to my next question. Thank you both for your submissions. The points that you raised in your submissions are very well received so I am not exploring those as much. My question is around the funding and effort that goes into medical research, particularly obviously in relation to rural health. My next question is going to be about Aboriginal health. Maybe both of you could address that. I assume more needs to be done. Professor, as you have just said, you cannot do everything that is there for your small team to do.

Professor SEARLES: I believe part of the solution is that this is where the education and training comes in. We actually do and have worked with a number of Aboriginal organisations not only in New South Wales but also in north Queensland. My view is that training and capacity building is essential. The way that I express it when I go in—and I go into health services myself; it is not just my team members—I often say it is like calling a plumber into your house where you point to the problem that you have got. We all go and work on that problem. I am not bringing my research to do in a health service. I will work on the health service's problem but, in addition, I will show you what I am doing so that if you have staff on board that are interested in doing this, we can go from that problem. So that they can start to do it elsewhere.

The example that I have is with the local PHN. I spent three months sitting with our local PHN. At the very beginning, evaluation was very new for them. After I left the PHN, I had shown them how to do a very basic cost-benefit analysis, which is a form of business case. A couple of months later I was sent an email from our local PHN asking if I would review the cost-benefit analysis that they were putting forward to the Commonwealth. It was a really nice piece of work. It was a really concise business case of what it is that they wanted to do.

To my way of thinking, that should be the philosophy of what we are trying to do. It is not building up a whole lot of consultancies; it is actually upskilling the health staff because they really do want to be able to do this themselves. There are times when you need arm's length between the person doing the evaluation and those providing the service. I think there is a little bit of a grey area as to where that is, but clearly when they are large investments you probably do want an external person doing the evaluation. But for many of them, if we are going to make this business as usual, we want the health staff to be generally—even if it is only that they know what the evaluation is entailing, so that when they go out and ask somebody to do it they know what they are asking for.

Ms CATE FAEHRMANN: It is a very good point. Dr Stephens, did you have anything else to add there?

Dr STEPHENS: I will just add very briefly, in terms of research priorities—and I will speak to this from the perspective of a local health district in rural and remote New South Wales—undertaking research that will assist the LHD in meeting its strategic objectives is a priority. It is a priority for me in my role as the director of research for my particular LHD. I think the issue of funding is complicated. It is a very competitive space. I think we are working strategically to try and promote, I suppose, in a way, research that will assist health services in meeting their core functions in terms of delivering health care. I can speak from the perspective of the alliance. We are working very closely with the Office for Health and Medical Research to develop a research strategic plan for regional and remote areas. We are also working closely with them to be able to deliver on the recent Medical Research Future Fund grant to improve access to clinical trials in regional and remote areas.

The CHAIR: Thank you.. We will move to the Hon. Wes Fang, who I think has some questions.

The Hon. WES FANG: Absolutely, Chair. Thank you very much. I could sit here all day and ask questions of Dr Stephens about his research. I think it is fascinating. Dr Stephens, I was actually hoping you might be able to provide just a bit more of, I guess, some of the meat that you have had from the research. In the short amount of time we have got, we have only got a few minutes left—

The CHAIR: Just take your time. It is okay.

The Hon. WES FANG: Thank you, Chair. I appreciate the latitude. Just some of the, I guess, take homes for those people who are not able to dive right in to it. What is it that you see as the real take-home message from what you have been researching?

Dr STEPHENS: My research is just one small example of a general approach we should take for better defining and identifying what the real problems are in terms of explaining those health deficits and that health divide between metropolitan and rural areas. To be perfectly frank, I am now quite far removed from my research. My day job takes up all of my time and I have to do my research basically as a hobby. But the underlying principles are that it is a complicated issue. Right? There can be differences in health between metropolitan and rural and regional areas. That is fact. It is out there. There are a number of metrics you can look at that provide strong evidence to show that.

The next challenge, I think, is being able to take the next step and determining if we are going to make a change to the way that we deliver health care or do anything in regional and remote areas to act on that deficit and potentially improve it, how do we go about doing it? It is going to be a complex issue. It is going to be permeated by social determinants, and this very inquiry has revealed throughout its course also a number of issues. Some of them may be anecdotal and some of them may be based on more thorough high-quality evidence, but they are all things potentially that are worthwhile investigating.

I guess it is up to you as our elected members through this inquiry to make recommendations as to the next steps. I would basically just advise that this is the starting point. We can highlight what the issues are, identify the priorities, but we need to drill deeper to then tailor solutions to best address them, understanding that we operate in a world where we have finite resources; they are not unlimited. Some of the work that Andrew is doing really nicely complements what I have been suggesting: We need to understand, if we are going to do something, what is going to result in the greatest impact for the best cost or return on investment, and that we continue monitoring and evaluating through the capture of routine data.

The Hon. WES FANG: What you are effectively saying is that a lot of the issues are complex and that those people who seek to simplify it down to a sound bite, for example, are probably not doing justice to the complexities within it. Would that be a fair assumption?

Dr STEPHENS: I would say that is 100 per cent correct. We can even look at the sessions run today—with the cancer inequalities this morning and the Medical Staff Executive Council and Indigenous health, and now what we are talking about with the research. They all highlight that there are probably different drivers all contributing to some of the health deficits and inequalities that we see. So, yes, I would suggest it is a complex issue, but we need to probably take a prudent scientific approach to be able to, I guess, equip us with the tools necessary to address what are the biggest gains to be had.

The Hon. WES FANG: In the last minute that we have got before we end, I just wanted to ask how you would respond to those who might seek to make political gain from attacking research that you might have undertaken in order to further their political agenda?

Dr STEPHENS: I would probably just recap that what I was trying to communicate is that there is a complexity to the health inequalities and my example there of adjusting for socio-economics status in no way discounts that there is a health deficit observed in regional and remote areas. It just reveals that there is probably an underlying complexity there that may account for that particular metric of population health. Right? That is one of many metrics. It is just sort of introducing the concept that we need to leverage off research to identify what the causal problems are.

The Hon. WES FANG: My take home from that is that you think they are obviously trying to simplify it and it is not simple. It is quite a complex issue. Thank you so much for your evidence today, for the research that you have done and for providing some time to give us your insights. I very much thank both of you for assisting the Committee.

Dr STEPHENS: Pleasure.

The CHAIR: Gentlemen, that brings us to the conclusion of our time for questions. It has been a very fruitful exchange. There was much thought behind the questions and the information that has come back has been very detailed, such that there is the possibility of some supplementary questions after the Committee members have had the chance to read the *Hansard*. If you are agreeable, what would normally happen is the secretariat would liaise with you with a turnaround time of 21 days for those supplementary questions. Once again, on behalf of the Committee, I know you are both very busy and we thank you for making time available this afternoon to provide some oral evidence.

Professor SEARLES: Thank you for the opportunity.

Dr STEPHENS: Thank you, Chair. Thank you, Committee.

The CHAIR: That brings us to the conclusion of today's hearing. We do have another hearing tomorrow. It will commence at 9.15 a.m. We look forward to people, if at all possible, continuing to follow the course of the hearing with us tomorrow.

(The witnesses withdrew.)

The Committee adjourned at 15:00.